

Thesis
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'They come here to tangle':

**An ethnographic study of relationships of
people with dementia**

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Abstract

This is a sociological ethnography of nine people with dementia living in a private nursing home in central Scotland. It seeks to find an alternative way to view people in this situation, in a field that has been dominated by the medical model. By placing the people before the disease of dementia, they can be studied within the same framework as any people. For this study this framework is everyday life sociology with a focus on symbolic interactionism, ethnomethodology and dramaturgy. Additionally, by gaining the subjective perspective, we can get close to understanding meaning for these people. The ethnographic methods I use consist of participant observation and interviews. For analysis I employ NUDIST to structure the data and the thesis. The setting, Lavender Wing of Deer View Grange Nursing Home, provides context for the study. This is a culture of surveillance and routines, which can be restrictive, infantilizing and disabling for residents. Despite this culture research findings are of socially active participants. By examining relationships through an interactional framework three thematic areas developed concerned with emotions, interactions and classification. These thematic spheres demonstrate the emotional self, the interactional self and the generalized self of research informants. The emotional is concerned with the most inner and intimate self, often engaging in backstage intimacies and in thought. Significant others share with the interactional self, in frontstage performances, which are more ritualistic. The generalized self interacts with the generalized other, most often consisting of everyone in Lavender Wing and is concerned with classification and boundary definition. Within these

spheres the described relationships are fluid and change according to the situation, and how participating actors define it. To engage in intimacies, rituals and form, and to shift between them requires social competence and active participation. People in this study demonstrate these. Despite restrictions they offer resistance to the environment and to dementia. They often make profound and metaphorical statements, to which this ethnography gives voice.

Keywords

Everyday life; interaction; nursing home culture; people with dementia; resistance; self and others; social competence; surveillance.

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Chapter 1: Introduction

This ethnography is about people. That is something I want to state at the outset. Specifically, it is about the people most directly affected by dementia, those who have it. They are the focus of this study.

This account seeks to explore from a position of minimum pre-conception. The study from which it grew was in enthusiastic response to a new Centre for Social Research on Dementia, which was established at the University of Stirling towards the end of 1997. The Centre's aim is to redress the balance in knowledge about dementia, which has failed to take account of social factors. Organized into themes, projects were already under way to meet the Centre's aim and were concerned with evaluation and early detection of dementia. The theme that was not being covered was concerned with 'The social meaning of dementia'.

I joined the Centre as a research student in 1998, with a background in sociology, an interest in relationships and little knowledge of dementia. As I had not come across a wide sociological literature concerning dementia, there appeared to be scope to develop a study in a relatively new area of research making use of my existing interests. Additionally, it seemed that branching into this new area of seeking the social meaning of dementia also required development of appropriate methodologies. This would also contribute to a further theme of the Centre for Social Research on

Dementia: 'methodological issues and developments in researching dementia'.

My interest in relationships provided an appropriate means to explore the social meaning of being a person who also has dementia. I wanted to gain a depth of understanding of this and wishing to explore the subjective view, I needed to go beyond third party accounts used by others, or engagement in role play and to learn at first hand from people who had dementia. My first aim, then, was to study the subjective perspective on dementia.

My aim determined that it should be a qualitative study because of the depth of information required, and this in part determined my choice of setting and my methodologies. After considering a number of options, I felt that what I was trying to learn required continuous study over a period of time. I did not want snapshot views of an instance, which would not allow me to get to know individuals. If I were to achieve understanding through relationships, this also needed to be set in context of individuality and difference, rather than treating all the people in the study as an homogeneous group.

A number of decisions about the research design were made simultaneously, as the method suggested the setting and the setting suggested ethnographic method. I also felt that study for my doctoral thesis might be my only opportunity to conduct ethnography, as funding for this type of research is often difficult to obtain. The appropriate setting for

the research became determined as one where a number of people with dementia live. Many such settings house older people, some of whom also have dementia. The setting I chose was a nursing home where all the residents have dementia.

My second research aim did not become established until after I had met my research informants and also read academic literature on dementia. There was a conflict in the information I was getting from these two sources. The literature spoke of decline and loss associated with dementia and these images provoked fear. It was indeed, a dismal picture to gain before starting fieldwork and I was very apprehensive about this. Perhaps because of the negativity of the literature, it was something of a surprise that residents in the study appeared as people. They talked to me, they looked like other older people and there did not seem to be reason to fear them. I wanted to be able to convey this impression to others, that people with dementia are still people and they should not be feared. I needed to show that they have characteristics of people and I now wanted to determine that these residents were active social participants.

These became my research aims: to explore the subjective perspective of dementia and to determine if research informants were active social participants. In the thesis, using ethnographic method I attempt to construct the subjective view of people who have dementia. I use their words when possible, and I express what they have told me and what I have seen. I interpret within the theoretical basis of the study and in the context of the

setting. By studying in a nursing home I have sought to find what everyday life may be like: to understand the social world for someone who has dementia.

The words of one research participant provide the title for the thesis: 'They come here to tangle'. This expressed what life in a nursing home was like for her on some days and it is said in her voice. The context in which this was said provides the meaning of the phrase. She was talking about people coming in and out of the lounge in which we were sitting, as often occurred. She was using a substitute word, which was also a frequent occurrence, which had a similar meaning to 'mix' or 'socialise'. The phrase summed up, more eloquently than I could, what the thesis is about, the relationships of people with dementia living in a private nursing home.

That this title came from a research participant highlights a key element of ethnography and specifically of this study. This element is voice, which both expresses subjectivity and shows social meaning. I do not seek to liberate or empower the people involved in the research. I am attempting to project an image that may help to produce alternative views to those that focus on disease rather than people. Two ways in which this may occur are by facilitation of voice so that people with dementia can express themselves and their preferences, and by finding ways in which others can hear what they are saying. Through ethnographic writing, residents' words and expressions can be given permanence. It is my hope that this will

advance our understanding of the social meaning of dementia and that we will learn to hear what people with dementia say.

Having provided some rationale for my approach and the subject area I now outline the rest of the thesis.

Arrangement of the thesis

With research aims established above, in Chapter 2 I ask 'Whose dementia is it?' This is focused theory considering different perspectives and attitudes to dementia. By examination of what perspectives have been used to date and the resulting attitudes that these have produced, then thinking in alternative ways, we can see how perspective frames impressions. This is also a way of examining how a perspective for social research on dementia may look. Relationships and social support are discussed. In this study, there are other considerations that also have to be examined relating to the culture in which residents live. Power, control and surveillance, and rules and resistance all relate directly to the environment, have relevance to residents and are a part of everyday life for them.

Having now positioned the person before dementia, Chapter 3 moves into the social world of everyday life, exploring the theoretical background for the study. This study is about people who have dementia, but because primacy is given to the fact that they are people rather than that they have

dementia, then an appropriate theoretical framework is one appropriate for any group of people. It is a study of everyday life, and a number of theories provide this framework. Aspects of symbolism, interaction, strategy and dramaturgy are considered together with emotions, to explain how shared meanings are conveyed and understood. Ways of defining are also important, including labelling, self-perception and boundaries. These constitute the basis of the background theory for the ethnography.

As limited work has been completed to date that takes account of the subjective perspective on dementia, appropriate methodologies need to be found. Chapter 4 is concerned with methodology. The way that the research is conducted is important for the facilitation of voice. In addition to considering how to gather the data, other matters relating to access, ethics and consent are discussed. These are relevant to all research but the sensitivity of them is highlighted when research participants are also considered to be vulnerable, as in this case. There may therefore be implications in these methodological considerations which go beyond the scope of this study.

The above chapters form the basis of the background to the study, which constitute Part A of the thesis. Part B is concerned with ethnographic description. Conventions used in writing this are outlined in Chapter 5. This is the first analytical chapter and relates to introduction of the setting and research participants. Analytical themes emerged and developed during fieldwork on the basis of the two research aims of gaining the

subjective perspective, and exploring active participation amongst residents. The significance of the nursing home effect on social activity became apparent and is the topic of Chapter 6. Drawn from empirical evidence during the study this gives further context to it. Further empirical data led me to analytically develop three substantive themes which all related to and emanated from subjectivity.

The first substantive theme area is shown in the analytical chapter relating to 'Emotions and dementia' in Chapter 7. The first aspect of the active social participant is displayed as emotional. This concerns the most inner self, relating in backstage performance. A range of emotions is considered as arising in research. Some emotions appeared connected to or accompanying aspects of dementia and are discussed in relation to confusion, wandering and awareness of dementia.

The second aspect of the active social self is revealed in interactions, the subject of Chapter 8. More formality and frontstage performance is often associated with these. Frequently involving ritual, they present an opportunity to examine social competence and participation.

Boundaries and boundary definition is the theme of the third analytical chapter relating to active social participants, Chapter 9. Here consideration is given to physical boundaries, self and other, and the situational domains arising from frontstage, backstage, inside and out. Restrictions arising out of the nursing home culture and from dementia can place residents in a

confinement situation, but it is one they can be seen to resist in various ways. Finally, the boundary situation of liminality is given consideration in relation to older people who have dementia.

These analytical chapters of Part B provide evidence to satisfy the research aims of gaining the subjective perspective of dementia and examining active social participation of research informants. Voice is given through ethnography, and social competence and active participation are shown.

Having outlined the arrangement of the thesis, more detailed scene setting can now begin. This will start with the examination of theory relating to the person with dementia.

Chapter 2: Whose dementia is it? Power, control, rules and resistance

The examination of the social world of research participants is set in context by investigation of perspectives on dementia, and the differentials in power which may cause vulnerable people to be controlled and subjected to rules. In the past, dementia research has been undertaken predominantly from the medical point of view, which places disease before the person, and is phrased in terms of loss and decline. This perspective sees people who have dementia as passive recipients of care. Alternative models could dispel stereotypical images conjured by negative views of ageing and dementia and show these people as active, and able to offer resistance. When the subjective experience of ageing has been studied, for instance, people have expressed the view that they feel veiled in a 'mask of ageing' rather than feeling, as stereotypical images of ageing suggest, old and useless. To understand what it is like to have dementia from the subjective experience will similarly reveal emotions which have been masked in perspectives described from the point of view of others.

Disability studies will be explored to provide lessons in how we can progress towards a model for social research on dementia. Relationships and social support will be discussed to aid this progression and our perceptions of people who have dementia.

Furthermore, the social world of people who have dementia and are participants in the study, needs to be set in the context of the environment in which they live. The use of surveillance and control within nursing homes demonstrates inequalities of power in relationships, which maintain residents in subservient and vulnerable positions. Rules are an intrinsic part of this environment. However, I wish to show research participants as active and able to make effective escape attempts as a means of resistance to everyday life.

This chapter is key in setting the scene and raising concerns for the study. It introduces issues which will develop throughout the ethnography, starting from conventional accounts of dementia.

Conventional accounts of dementia

If we are to gain a sense of what dementia means to the everyday lives of people who have it, and those who care for them, an exploration of fiction and personal biographical accounts may be useful. Hepworth (2000) has explored *Stories of Ageing* as a means of understanding the ageing experience. Amongst many of the fictional accounts he examines are those of dementia. As he points out:

Because of the variety of perspectives which are possible in imaginative fiction the reader may be guided towards a deeper understanding of the person with dementia. Hepworth, 2000: 16.

The subjective view is difficult to gain and understand, and fictional imagination thus allows the construction of what it may be like to experience dementia. The use of various perspectives adds to the image

and also gives context to the experience. Individuals may be shown 'in the rich context of their family and social life', and often from the perspectives of different actors (Manthorpe, 1996: 27). Relationships feature strongly in fiction and demonstrate the intimacies and subjectivity of those involved.

Two women's voices narrate in *Have the Men Had Enough?* (Forster, 1990). Their relationships to 'Grandma' who has dementia, are daughter-in-law and granddaughter. The story is one of love, obligation and the turmoil created by dementia for all concerned. The characterisations show the elderly lady with dementia and her principal carer as vulnerable and not coping, almost inevitably leading to the need for residential care. Fears and guilt feature strongly. Grandma clearly has a voice and is given character by the author, yet when decisions about her life are made her voice is silenced.

A son's story is told in *Scar tissue* (Ignatieff, 1994). This also is a study of relationships and the impact that dementia can have on them. His mother has dementia and his parents grow closer through this: dependency creates a bond. Conversely, as he attempts to help his parents, his own marriage partner and young family become more distant. The story shows decline, loss, and a disparity of perspectives between a son's concern for his mother's well-being and the neurologist who reduces her to a case-study.

Both of these novels are well enough researched to allow the reader to identify with the experiences that dementia presents. Some additional insight into dementia can also be gained from accounts written by people in the early stages of the condition (for example Davis, 1984; McGowin, 1993; Rose, 1996). The titles of each of these books suggest journeys into dementia, being engulfed and lost, and wishing to go home. Davis describes memory difficulties, panic and confused emotions:

I feel both good and bad emotions at the wrong times ... there is little or nothing that I am capable of doing to change my emotional feelings. I simply have to live through them and continually discount the effect they have on my judgement. Davis, 1984: 109.

This perceived effect of emotions upon rationality is interesting, and a common characterisation of people with dementia. McGowin went through many emotions after she was diagnosed with Alzheimer's disease at the age of 45 years. Many of these were concerned with the relationships she had with others and how these changed as a result of her diagnosis. She also felt a sense of loss, consistent with suggestions in academic literature that will be seen later:

... there are many days when I am painfully aware that less of me exists than the day before. McGowin, 1993: 116.

The sense of loss is also echoed in two biographical accounts by daughters of people with dementia; *Losing the Dead* (Appignanesi, 1999) and *Remind Me Who I Am, Again* (Grant, 1998). These accounts have been described as 'confessional' and presenting 'a whole series of perceptions' (Manthorpe, 2000: 35). I found that they were concerned with the relationships between mothers and daughters. As their mothers' memories fade, they try to (re) construct their pasts, ever conscious that part of their

own biographies is tied to those of their mothers. This may be a vital clue to the association of loss of self for people with dementia, that the practice of gaining second-hand accounts of dementia will reflect the sense of loss that others feel.

Both also illustrate the complexities of mother and child relationships changed by children reaching adulthood and appreciating that their parents had pasts and features not seen by the children. Characterisations of their mothers show repetitive behaviour and questioning, as things are constantly forgotten.

As Rose struggled with her memory, her daughter struggled to come to terms with the dementia diagnosis she had been given, in the knowledge that their relationship had been less than perfect. Like many family members, Grant sought information about her mother's illness, in order to cope with it. She found that in doing so there was a sense in which she had learnt more about dementia than about her mother. She asks 'Am I talking to a person or a set of symptoms?' (Grant, 1998: 265).

This sense of the person being taken over by the medical disease may have been due to the absence of a close relationship and could have engulfed a relationship that was close. There is little evidence of this, however, in Bayley's works (1998; 1999). He cared for his wife, Iris Murdoch the author, through her Alzheimer's disease. His two books are of their lives and relationships before and with dementia. In reading them

there is a sense of serenity and acceptance of the condition. In caring for his wife, Bayley felt their relationship strengthened and grew closer. In a diary entry just over a year before she died he writes:

Every day we are physically closer; and Iris's little 'mouse cry', as I think of it, signifying loneliness in the next room, the wish to be back beside me, seems less and less forlorn, more simple, more natural. She is not sailing into the dark: the voyage is over, and under the dark escort of Alzheimer's she has arrived somewhere. So have I.
Bayley, 1998: 183.

The metaphorical journey features yet again, and the escort is 'dark'. In the above quotation, Bayley also illustrates how intertwined the lives of the person with dementia and carer become.

Equally interesting as these very personal views of the experience of dementia are those more widely held, popular characterisations demonstrated in the reports and obituaries following Murdoch's death. An analysis of these showed dementia as the tragedy of the loss of mental capacity highlighted for someone known for their intellect, and the projection of images on to Iris Murdoch (such as goodness) whilst she remains silent.

Some of the accounts portray the dementia in essentialist terms, suggesting that Iris was demented rather than that she had dementia.
McColgan *et al*, 2000: 107.

This highlights the pervasive image of the person being lost to the disease.

Attitudes to dementia can be seen through examination of fiction, accounts by both carers and people with dementia, and also press representations. The picture is one of changing relationships, turmoil, vulnerability, loss,

decline and darkness. Carers try to hold on to or recapture the past, and feel guilt and fear if residential care is needed. Tragedy, a person lost to symptoms, reduced to being a case-study and journeying into dementia, are common themes.

The voice speaking loudest is not that of the person who has dementia, even when imagination and creativity permit, but of others touched by the experience. The personal accounts examined also appear to be as strongly influenced by popular representations and expectations of dementia as by experience. For instance, Davis voices fears of what is to come, rather than describing what the current experience is like.

Perhaps the exception to this black picture is shown in Bayley's touching memoirs. There is sadness and a black side associated with Iris's dementia, but the books indicate as much about the relationship between him and Iris Murdoch, as about her experience of dementia. This is of particular relevance to this study. By focusing upon Iris Murdoch, the person and upon her personal biography, she is not obscured by the dementia she experienced for a small portion of her life. This focus, it is hoped, may also be indicative of wider attitudinal changes regarding dementia; changes which will be influenced in many ways and social areas, one of which is social research.

Before discussing the position of social research on dementia to date, it would be useful to examine other influences upon attitudes. One such area

of interest relevant to this study, and also to older people who have dementia, is that of age or more specifically old age which is grouped broadly as gerontology.

Age: stereotypes and images

Age, and particularly old age, is also subject to characterisations and stereotyping 'constructed from a complex blend of discourse and sensory images' (Featherstone and Wernick, 1995: 5). When one group applies these stereotypical images to another it amounts to prejudice; when this is related to chronological age, it is ageism (Bytheway, 1997: 3). Whilst ageism is not exclusive to old age, this is the main way in which the term is used, and therefore has relevance to participants in this study.

Ageist assumptions about older people relate to moral panic and 'the dependency ratio', which is based upon economic activity and defined in terms of working ages. Thus people are defined as dependent when they are under 16 and over 64 years old (Bytheway, 1997: 52). However, children are seen as potential assets whilst older people are not. Blaikie points out that ageism arises both in social structures, as seen in policy, and in individual attitudes. These are legitimised by 'ideological supports' through 'biological reductionism', 'psychological explanations' and 'social justification', which deny rights, create dependency and suggest that older people 'want to disengage from society' (Blaikie, 1999: 17).

All of these are the ways that others perceive older people, and by virtue of the fact that a sense of self is often defined by reflections from others, or relationally to them, then negative stereotypes can impact on self-image. However, inner consciousness and outer bodily appearance often conflict in old age. This is described as the 'mask of age' (Hepworth, 1991).

When we catch a glimpse of ourselves in a mirror we are often surprised by the image we see, that we do not outwardly appear as we feel inside. This has been described as the 'mask of ageing' (Featherstone and Hepworth, 1988; 1990; Hepworth, 1991), a description of the disparity between the 'inner' self and 'outer' projection. Ageist assumptions are constructed on the basis of our physical appearance:

... it is the ageing mask which is pathological or deviant and the inner essential self which remains — even beneath or 'inside' Alzheimer's disease — as normal. Featherstone and Hepworth, 1988: 379.

Negative stereotyping of old age is related to culturally valued images of youth which are specific both temporally and culturally (Featherstone and Hepworth, 1990: 274). This specificity identifies them as socially constructed.

It has been shown that stereotyping of dementia and old age stigmatise older people with dementia, and that the views of old age differ from the subjective view. Both have a disabling effect, which becomes doubly so when older people experience dementia. This impacts on self-image, and causes tensions between the inner and outer person. These tensions may become more pronounced with a move into residential care in which life

becomes more public than private, and more involved in frontstage performances. In this sense the environment also has a disabling effect on the person who has dementia and finds themselves in unfamiliar surroundings. This is a point I will return to later.

Medical model of dementia

Much of dementia research to date has been from a medical perspective. It is worth examining what this means before looking at critiques of this attitude. The medical model of dementia starts from a scientific base and claims objectivity. It is concerned with dementia as disease, which immediately defines it in pathological and problematic terms.

In terms of dementia as illness:

Dementia is a syndrome which may be caused by a number of different illnesses. It is a progressive failure of many cerebral functions.
Jacques and Jackson, 2000: 1.

The different illnesses affect individuals variously. What the syndrome has in common is a decline in mental faculties. Occurrence of diagnosed dementia is low in people under 65 years old with percentages rising in each older age group above this. Prevalence is at over 30% in the over 90 year old age group (Jacques and Jackson, 2000: 3).

Causes of dementia include Alzheimer's Disease, where plaques and tangles develop in the brain and interfere with the transmission of messages sent between neurones, and multi-infarct or vascular dementia caused by a series of strokes affecting the supply of blood to the brain.

Other illnesses include Lewy body dementia, Parkinson's disease and Pick's disease. Tumours, repeated head injuries, alcoholism (causing Korsakoff's syndrome), AIDS, Creutzfeldt-Jakob disease (CJD), vitamin deficiency and Binswanger's disease can also cause dementia or dementia-related conditions (Berrios and Freeman, 1991; Gubrium, 1986a; Jacques and Jackson, 2000). Some of these conditions are reversible or may abate if the cause is removed. This would be dependent on early diagnosis and treatment. Most, including the two most common, Alzheimer's disease and vascular dementia, are not reversible. In these medical terms, dementia is caused by degenerative diseases, which can only be seen in terms of decline.

At the start of my investigation for this study, I contacted various sources to gain background information, one of which was a group that offered support and advice to people with dementia and their carers. After I had explained what I was doing, the advisor immediately told me that the very first thing I should do would be to view a video called 'Brain and Behaviour'. This video is described as being 'about how dementia as an illness affects brain functioning' (Publications List, Dementia Services Development Centre, 2001). I have not watched this video and am disturbed that advice of this sort should be given to carers, or people who have dementia. What it does illustrate is that even for a group sensitive to the needs and wishes of carers and people with dementia, it was accepted that the medical model forms the only basis for understanding dementia. My main objection to viewing the illness of dementia before anything else was that it might

influence my social view of people with dementia. In a sense, I feared that it would label people with dementia as diseased.

As will be discussed in Chapter 3, different actors have different objectives in labelling people as having dementia. Carers may be seeking an explanation of unusual behaviour. People labelled as mentally ill envisage collusion in the diagnosis procedure between family and health professionals (Goffman, 1991). But carers seek an explanation for what may be considered as unusual or changed behaviour, and this is often satisfied by diagnosis.

The benefits of labelling of dementia are not so clear for people thus labelled as they are for their families. There is also a danger that, once labelled, all behaviour will be attributed to dementia. As Cheston and Bender point out 'a diagnosis identifies an individual as a member of a specific group of patients' (2000: 50). They also say that 'the process whereby a diagnosis is reached is inevitably a subjective one carried out by fallible human beings' (Cheston and Bender, 2000: 50).

The problem of the disease model is in the way we perceive the person labelled as having dementia. The prospect of decline is expected, as is incompetence, and the person does indeed appear lost to the disease. Framing dementia research within the medical model thus obscures the person behind the disease, and guides the way that dementia is perceived. It has been criticised for this:

... the person with dementia is often relegated to the status of object rather than legitimate contributor to the research process.
Cotrell and Schulz, 1993: 205.

Seeking the subjective perspective, is one step towards redressing this imbalance.

The medical model undoubtedly informs commonsense understandings of dementia, as seen in fictional accounts which include dementia, and which have already been discussed. Challenges to the medical model of dementia have been made as they have in other areas of research. A review of these will move us further towards a social model of dementia.

Learning from disability studies

The fields of social research on dementia, and that of gaining the subjective view of dementia, are still relatively new compared to other areas of research. There may be valuable lessons that can be learnt from these areas, which may help to inform social research on dementia.

In the area of learning difficulties, strategies have been developed to help empower people. Duckett and Fryer (1998) and Stalker (1998) have employed people with learning difficulties directly in the research process, in an attempt to aid empowerment. Not only is the subjective view of learning difficulties gained, but it also becomes a part of setting the research agenda.

However, Bowes (1996) has identified problems with empowerment in 'anti-racist sociology, feminist sociology, and action research'. She points out that the concept of empowerment of those being researched has been thought of 'as a universal good'. This term echoes paternalism and as Bowes states is in danger of:

... increasing the arrogance of research, as researchers may believe they have the power to emancipate, by giving power.
Bowes, 1996: 5.

I make no claim to attempt to empower participants in this study, but I do believe we need to find appropriate ways to give voice to people with dementia. This is the purpose of this ethnography and will be discussed more fully with other methodological considerations, in Chapter 4.

Empowerment and liberation from social oppression have been common themes emerging in the relatively young area of disability studies. Because disability studies are young in comparison to the sociological theories that I am using, but more developed than dementia studies, there may be important lessons that can be learnt.

Part of the basic tenet of disability studies is a critique of models variously called 'individual,' 'personal tragedy' or 'medical' models of disability which locate 'the problem of disability within the individual' caused by:

... the functional limitations or psychological losses which are assumed to arise from disability. Oliver, 1996: 32.

The alternative social model of disability arising in opposition to this is based on:

... the distinction between disability, which is socially created, and impairment, which is referred to as a physical attribute of the body. Corker and French, 1999: 2.

Although the development of the social model which arose out of work of little more than twenty years ago by Finkelstein (1980) and Oliver (1990), initiated a proliferation of other disability models, it remains 'definitive of the disability studies approach' (Shakespeare and Watson, 1997:293). But it is also open to questioning (for example Morris, 1991; French, 1993; Crow, 1996).

It is clear from Oliver's work (1990, 1996) that the social model of disability developed as a political lever to create changes in society which cause disability. Individual experiences of impairment have been silenced, so as not to reduce disability to the previous medicalization being criticised. Additionally, because of the impetus to create political change, there has been a tendency to 'favour a united line to competing voices' (Shakespeare and Watson, 1997: 299).

As a result of this tendency to project one voice of disability, for fear of diluting its strength (Finkelstein, 1996), other voices of disability have been silenced and non-disabled people have probably failed to understand the issues. Corker and French point out that:

... the way that most non-disabled people 'talk' about disabled people is often removed from disabled people's conceptualization of disability as a socially created phenomenon. Corker and French, 1999: 10.

It seems that the silencing of subjective experiences of impairments has, in fact, objectified disability just as medicalization did previously.

The social model thus has an exclusionary element excluding some disabled people. As French (1999) points out, some of her disability is due to her visual impairment, in her failure to recognise people and the inability to detect body language and social cues. Exclusion of the impairment element from the social model, also excludes her.

Disability is caused by 'social attitudes' and 'environmental barriers' but:

... to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. Morris, 1991: 10.

The social model of disability clearly fails to be inclusive.

A reassessment of the social model of disability is taking place as a result of these criticisms and is reflected in edited volumes giving voice to previously silenced disabled people and through narrative (for instance Barnes and Mercer, 1996; Corker and French, 1999). There is a recognition that the social model of disability should now be made 'accessible to a wide audience' (Barton, 1999: xi). This involves getting the views to non-disabled people and from a diverse range of disabled people, to establish:

... a disability discourse that is multi-layered and able to reflect voices which, it is claimed, have been hitherto silenced, borderline or unfamiliar. Barton, 1999: xi.

Speaking as a non-disabled person, my empathy and understanding was greatly increased by reading the narratives of impaired people (Boazman, 1999; French, 1999; Slack, 1999). It also gave more insight into how

disabling their conditions are made by others and the value of obtaining their subjective view. For instance French (1999), recounts a personal experience of being on holiday with a visual impairment. Sensitive treatment by her travelling companions allowed her to participate on her terms; the disability of her impairment was reduced.

The disabling effect of aural impairment did not exist at all in Martha's Vineyard, a community with an unusually high incidence of deafness (one in 155 compared to one in 5728 more widely in US). Even families without deaf members used sign language as required, not only to deaf community members, but also in situations when verbal communication was difficult such as in windy weather, in school or in church. Groce (1985), in a study of this community found that deaf people were not in fact considered as disabled, different, or deviant. The deviant was the person who could not sign (Groce, 1985:56).

The widespread use of sign language affected every aspect of Vineyard society ... There was no language barrier and, by extension, there seems to have been no social barrier. Groce, 1985: 75.

The case of Martha's Vineyard serves to illustrate that it can be society that disables impaired people, rather than their impairment.

The denial of individual narratives or discussion of needs relating to an impairment may be the key to the misunderstanding of disability by non-disabled people. Appreciation of the issues may be conveyed by the inclusion of subjective experiences as expressed in Corker and French (1999). Another problem arising from the social model of disability, and

one from which dementia studies could also learn, is by 'parceling off disability into a separate academic domain [it] maintains the fiction of its difference and distance' (Gordon and Rosenblum, 2001: 16).

The study of disability is a complex area, perhaps made more so by 'internal dissension' (Shakespeare and Watson, 1997: 299). If it is:

... to produce the kind of socio-cultural change which is its task, it must significantly increase both its *prestige* and its *status* by directly engaging with hegemonic structures and practices. Corker, 1999: 193.

This valuable insight, which points to failure to engage with sociological arguments and perspectives, also indicates what could happen in dementia studies. There may be a case, in trying to initiate social change, for development of a separate field of study. But, it seems a clear lesson from the area of disability studies that inclusion in mainstream sociology may also help in the development of inclusion of excluded people in more established theoretical arguments and ultimately in policy decisions. This strengthens my conviction that it is right to study people who have dementia within the same framework as any other group: through everyday life theories.

Some people with disabilities are able to engage actively in the promotion of the social model in disability. It is more difficult for people with dementia to do so: any change must originate in societal attitude, ironically what the social model is aiming to achieve. I feel this would best be done through incorporation of the dementia element into mainstream sociology, along with other aspects of social differentiation.

Social research on dementia

I have discussed how the social model of disability has grown out of a direct critique of medicalization in Britain. Yet there is evidence that this has not occurred in the USA (Gordon and Rosenblum, 2001: 16), or gained full acceptance in Britain (Shakespeare and Watson, 1997). Now, I wish to turn my attention to the state of dementia research to date.

Until the mid 1980s academic literature relating to dementia was dominated by the medical model and the basis of this has already been discussed. Initial questioning of the way this pathologises dementia was made by Gubrium (1986a). He debated whether Alzheimer's disease may be classified as a 'normal' part of ageing, and suggested that neurological and behavioural evidence could be used to support it being either ageing or disease. This appears to be the first indication that dementia may be considered pathological as the result of labelling and also that dementia may be socially constructed.

A further indication of Alzheimer's disease being socially constructed came in Lyman's critique of the biomedicalization of dementia (1989). She points out that Alzheimer's disease only 'emerged as an illness category and policy issue in the 1980s, more than 70 years after Alois Alzheimer documented the first case' (Lyman, 1989: 597). This was due to 'senility' being regarded as a normal part of ageing until this time.

Socially constructing dementia helps people make sense of the chaos of living with dementia (Gubrium, 1986a; Lyman, 1989) and counters the 'longstanding ageist assumption that senility is an inevitable condition of old age' (Lyman, 1989: 599). Bond (1990) echoed Lyman's criticism that the medicalization of dementia failed to take account of social aspects of the condition.

An indication of the direction that dementia research has now taken in Britain came with a book produced on 'The Social Construction of Dementia' (Harding and Palfrey, 1997). This must have been read by many health professionals with a recognition that this was now where dementia research was positioned.

Another aspect of dementia research is that until recently the subjective perspective of dementia has been absent. A proliferation of literature has focused on the carer's perspective (for example Gubrium, 1986b; 1988; Lyman, 1993; Orona, 1997; Rapp *et al*, 1998; Wuest *et al*, 1994). The images produced by these works have been of loss of self (Cohen and Eisdorfer, 1986), and dependency in guises of 'excess disability' (Sabat, 1994) and 'infantilization' (Lyman, 1993).

There have since been calls for the subjective experience of dementia to be explored (Cotrell and Schulz, 1993; Kitwood, 1997; Stalker *et al*, 1999). However, little to date has directly involved the person with dementia as

informant in the research process, in the way that has occurred in the field of learning difficulties (Duckett and Fryer, 1998; Stalker, 1998).

The call for the subjective experience of dementia to be taken into account continued throughout the 1990s. Many of the criticisms of the medical model of dementia resounded as Cotrell and Schulz (1993) pointed out that 'the person with dementia is often relegated to the status of object rather than legitimate contributor to the research process' (Cotrell and Schulz, 1993:205). Sabat and Harré (1992) challenged the loss of self for people with dementia, saying that if this does occur it is due to the ways in which others treat people with dementia, an argument in harmony with the social model of disability.

There are limited examples of research that has attempted to ascertain the subjective experience of the person with dementia. Keady and Gilliard (1999) sought the views of 15 people in the early stages of dementia who were aware of the diagnosis of Alzheimer's Disease. Cheston (1996) explored narratives of two people with dementia focusing on experience and metaphor and the way these are used to create social identity. He points out that by hearing voice through the representations of dementia we do not have to listen to what is said. By also considering the context in which people with dementia talk more meaning can be gained, but:

Attending to such meaning is inherently painful, as it forces us to acknowledge issues to do with loss, fear and isolation. Cheston, 1996: 599.

Downs (1997) also notes *The Emergence of the Person in Dementia Research*, in a review article. In this she focuses on:

the individual's sense of self; the person's rights' and the value to be gained from a concern with the perspective of people with dementia. Downs, 1997: 597.

This is a continuing reflection of repeated calls for subjectivity that is yet to lead to substantial studies. The call is not, as in disability studies, for more voices to be taken into account, but for any subjective voices to be heard (Goldsmith, 1996; Lyman, 1998; Sabat, 1998).

My own work has been greatly influenced by the area of dementia literature calling for 'personhood', putting the person with dementia first and giving voice to people with dementia (for example Cotrell and Schulz, 1993; Goldsmith, 1996; Kitwood, 1990; 1993a; 1993b; 1993c; 1993d; 1997; Kitwood and Bredin, 1992; Lyman, 1998; Mills, 1998; Orona, 1997; Sabat, 1998). Post's (1995) work and his comments on overemphasis on rationality and memory disadvantaging people with dementia is also pertinent to this study. This value emphasis on the mind is what makes dementia a disabling condition, because dementia impairs mental functioning.

Much of Kitwood's work is concerned with trying to place a different value emphasis on dementia care and research, by changing the paradigm from one dominated by an 'organic mental disorder' to a 'new culture'. The concept of 'personhood' with which he wished us to regard people who have dementia:

... is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Kitwood, 1997: 8.

He points out that people with dementia have the same needs and rights as everyone else, and that we have a moral obligation to treat them with dignity and respect.

Following from his study of dementia as 'malignant social psychology' Kitwood (1990) called for people to be placed before their organic condition. Not denying the impairments caused by neuropathology that dementia present to those who have it, he suggests their active involvement and moral commitment to the 'tragedy' is preferable to 'a blind and hopeless submission to fate' (Kitwood, 1997: 69). By this he means involving people with dementia in making their own choices and decisions, allowing them time to interact in their own way, and treating them with the sensitivity and respect of adults with a lifetime of experience behind them.

Personhood has through Kitwood's work become a key point of progress in treating people with dementia with more dignity and respect. It has put this issue into the public caring debate and focus just as some family carers, such as Bayley (1998; 1999), have conducted their caring for individuals. In Post's and Kitwood's terms personhood is concerned with including people with dementia, helping them to maintain relationships, through feelings, emotions and usefulness.

Images of dementia in social research have shifted from decline and disease towards personhood and hearing the voice. Part of the purpose of this current study is to move the images further along the continuum and show people with dementia as active social participants. Kitwood emphasised the value of relationships for people with dementia, and examination of what this means for this study will initially look at empirical evidence of relationships of older people.

Relationships

This section will examine the value of relationships drawing from examples of relationships of older people and people with dementia in other studies.

For the person with dementia living in a nursing home their relationship with staff, the people with whom they have the most contact, is subject to the culture within which they are living. Within the medical model, staff are seen as those with knowledge and therefore hold power which controls residents and reduces their autonomy. Residents also come into contact with visitors and other residents.

There is prestige associated with having routine ties with the outside world because this is a source of social news and residents are not seen as being abandoned. There is also a prestige associated with going out: 'Like having a visitor, visiting leads to camaraderie when a person recounts to others the details of events that occurred while he or she was out' (Gubrium, 1997:99). Gubrium identified a four-stage ritual associated with

going out: the announcement of the outing, continual reference and reminding of the outing, preparation of appearance to go out and the farewell or leavetaking. This highlights how much of an event an outing is for residents.

In addition to visible ties of relatives and friends from outside Murray Manor, through visits and outings, Gubrium identified hidden ties. Sometimes staff may bring news to a resident of someone they know outside. Similarly, visitors to one resident may bring news to another of people they know outside (Gubrium, 1997:104). In this way, networks from outside are still maintained, even if direct contact does not occur, or occurs only occasionally.

In relationships that are maintained for nursing home residents there is a clear distinction between family and friends. Family may collude with nursing home staff, and thus be in positions of power and control. Close family or primary kin are subject to obligation. Children, in particular, are seen as responsible for supporting parents as they get older (Allan, 1996:82), an obligation often causing feelings of guilt when a parent enters residential care. Friendship networks change routinely with no reflection on the relationship being flawed but as a 'consequence of the way the ties are socially organized' (Allan, 1996:95). Because of this difference in networking between kin and friends, when someone moves into residential care, the people who visit them most are more likely to be family than friends.

Friends are much more likely to be interest related. Through a shared interest, interaction between friends is likely to be expressive, and characterized by personal involvement (Jerrome, 1992, 72). Shared understandings and values bind and support peers and allow the opportunity to resist the pressures to conform. Outsiders are often keen to organize groups of older people in card games and the like, and resistance is often in the form of ignoring the organizer's commands to change card tables (Jerrome, 1992:178).

The difference in relationships between friendships which may promote resistance, and kin relations which are less likely to, highlights a key area of some relationships: that of social support. In the context of ageing, this may signify a change in dependency between children and parents. It is important to note, though, that social support is not an exclusive requirement of older people or dependants, but can be considered as an exchange within relationships.

Social Support

Throughout the course of this PhD study, I have known that relationships are key, and when asked what I am doing have usually described it as a study of relationships of people with dementia. The questioning would continue by asking what I meant. This is where I have always struggled. My interest grew out of an earlier study which looked at people who lived with dogs, and what the dogs meant to them. Although not such a detailed

study (an undergraduate dissertation), it appeared that people gained social and emotional support from their dogs and this was the case even when they lived with other people (McColgan, 1996). Whilst a larger and more detailed study would be required to prove anything conclusively, it was clear that social and emotional support are important factors to people in everyday life. As Kitwood's work suggests there is no reason why this would not also be the case for people with dementia.

Others see social support as important too. In a study of women in Camberwell in 1969 - 1971 and in the Outer Hebrides in 1975, Brown and Harris (1978) identified common vulnerability factors in the aetiology of depression. Realising that 'social factors act to protect and to make vulnerable' (Brown and Harris, 1978: 173), they asked about practical and emotional support received. They found that one of the most significant factors contributing to depression was the lack of a close, intimate and confiding relationship. Women were more at risk of depression following major life events that were considered negative, such as bereavement. Moving from home into a nursing home could also be considered in this way as it would also involve loss:

The availability of a confidant, a person to whom one can reveal one's weaknesses without risk of rebuff and thus further loss of self-esteem, may act as a buttress against the total evaporation of feelings of self-worth following a major loss or disappointment. Brown and Harris, 1978: 286.

This really sums up the aspect of relationships I was seeking to discover. In the adversity of being in an unfamiliar environment, of coping with having

dementia and possibly having lost spouses and peer group members through death, do people with dementia have social support?

In a different context, in Hochschild's (1983) study of airline stewardesses, social support was shown to be emotional and guarded against emotional strain. Emotional well-being could be seen to be engendered by offering backstage intimacies to balance against the frontstage performances.

The connection between social and emotional support also has relevance to Burkitt's (1997) suggestion that emotions are always experienced in the context of relationships. This will be discussed further in Chapter 3 in the section on emotions. But, if emotions are experienced in the context of relationships, then they also form the basis of social and emotional support.

Phillipson *et al* (2001) also point out that:

A key issue from research looking at influences on physical and mental health is the value of having someone to listen to one's troubles, and available to give support in periods of emotional stress. Phillipson *et al*, 2001: 119.

In order to determine what social support older people in their study had, Phillipson *et al* (2001) asked respondents eight questions, five relating to emotional support and three to instrumental support. The questions relating to emotional support were concerned with confiding relationships, asking advice, reassurance, and being able to talk to someone about health problems or when upset. Instrumental support questions related to help with household chores, financial help and transport (Phillipson *et al*, 2001: 118-119). In the nursing home situation instrumental support is

provided. What I am therefore concerned with is the extent of emotional support for residents.

Phillipson's *et al* (2001) work is a comparative study of older people's lives of the 1950s and today in three urban areas. In the recent research older people were asked who they received social support from and the nature of that support. Some relationships proved to be more key than others, with spouses being most significant for married people. Daughters were seen to provide more support than sons. Siblings remain important and nephews, nieces and friends join the main supporters for those who have never married.

The authors divided supportive relationships into four categories of immediate family, other relatives, friends and 'others'. Others included professional carers. These categories were hierarchical in their importance (Phillipson *et al*, 2001: 122). Support ranged from confiding relationships to being advisory or reassuring, or someone to talk to when upset or about health, or providing help with household chores, financial help and transport help (2001: 3).

Older people were also seen to place limits on the support they would accept:

... it was often revealed in responses to a question about whether respondents would consider living with a relative, for example one of their children. Responses to this question often highlighted the boundaries which people wish to maintain between themselves and even (or especially) close and intimate kin. Phillipson *et al*, 2001: 153.

This is an interesting point, and one often ignored, that people want to make choices even if they need some help. The reasons cited by respondents did vary but all pointed to matters of independence and choice; factors such as being able to smoke a pipe or being able to prepare a meal instead of being presented with one. There is a very strong sense of wishing to maintain independence.

Relationships are a key part of this ethnography of people with dementia, in a specific way, and for a number of reasons. Theoretically, relationships link strongly with interactions and emotions. The environment, issues of power and control, and shifting dependencies are all related to them. The specific aspect of relationships that I can identify as key to this study is that of social support which includes emotional support. Operating almost counter to this are the issues of power and control. They are the topic of the next section.

Power, control and surveillance

Power, control and surveillance are all related to panopticism; the gaze developed from the architecturally designed surveillance tower building by Bentham called the Panopticon (Foucault, 1991). Prisoners in cells are always visible from the central tower and because they do not know when the gaze of the supervisor will fall upon them, it is as if there was a constant surveillance. This situation is one of power and control from which the notion of panopticism developed. Anyone with access to the tower can

exercise the power of the gaze. 'The Panopticon is a marvellous machine which, whatever use one may wish to put it to, produces homogeneous effects of power' (Foucault, 1991:202). This use is wider than in prisons: the gaze extends beyond prisoners to other institutions and environments. How it is applicable in nursing homes is what I now wish to discuss.

Privacy in 'old people's homes' is discussed by Willcocks *et al* (1998). In a study of a hundred homes they found that only half the residents had their own bedrooms and in only two of the homes were residents able to lock these rooms from the inside (Wilcocks *et al*, 1998:82). They argue that without defensible space, ownership is undermined and as private space is outwith the control of residents it becomes common territory. In their study, they found there was little opportunity for residents to spend time unobserved by others and similarly little opportunity for visitors to talk in private with residents. This constant surveillance by others is a key component of nursing home living.

In Murray Manor, Gubrium (1997) found that individual residents and patients varied in how much they valued their privacy. 'Privacy-oriented patients are constantly vigilant over the boundaries between public and private places' (Gubrium, 1997: 33). People who do value their privacy have to work hard to maintain it, by keeping their room door closed and watching for intruders with no business. 'The result of not working for or being unaware of resources to maintain private places is a relatively public everyday life' (Gubrium, 1997: 36). As in the Panopticon, the opportunity

for surveillance is available to all. Lack of privacy allows inspectors, staff, residents, researchers and visitors alike to all engage in observation and also to be observed.

Gubrium makes a clear distinction between private and public places within Murray Manor as 'whether a person has been defined as the only claimant of a location's privileges' (Gubrium, 1997: 9). Residents may need assistance in private places: for instance, staff aids can enter to help toileting, but if they enter without purpose they are, in fact, violating privacy.

The justification for surveillance occurring and privacy lacking in nursing homes is also part of the culture of nursing homes. Nursing homes, including those for people with dementia, operate largely within a medical model. This is clearly observed by the seniority of nursing staff, the subordination of care assistants, and the routines, rituals and language used within them. In view of there being little medical treatment that can be given to alleviate dementia, if people are in physically good health then it is curious that this should be so.

Nursing home culture

The reasons for focusing my research in a nursing home are stated in my methodology (Chapter 4). It is worth saying at the outset that this is a place where people are living out their everyday lives and therefore it allows the opportunity to study people in their natural setting. People with dementia who live in nursing homes have usually lived some considerable time,

independently, outside of nursing homes. For the majority of people with dementia who live in nursing homes, dementia has precipitated a considerable change with the move into full time care.

Ethnographic studies of nursing homes which have started to appear in the last thirty years suggest that there is a specific culture associated with nursing homes (for example Gubrium, 1997; Lee-Treweek, 1998; Savishinsky, 1991), one of which is reflected upon in a collection of articles in *The Culture of Long Term Care* (Henderson and Vesperi, 1995). The growth in this area of research corresponds with that in the field of gerontology, sparked by demographic changes and an ageing population (Coleman and Bond, 1992). Combined they can produce a negative image of ageing giving rise to ageist assumptions of decline and dependency. I wish to argue that if older people living in nursing homes are considered to be a burden, the nursing home environment can often be responsible for this image and reflect it to society.

Through discourse, institutions such as nursing homes, are able to reflect and reinforce dominant values in a collective way. A theoretical scheme develops which, when viewed in the context of this discourse, makes categorization of even ambiguous elements appear natural and part of everyday life. Douglas (1986) suggests that through this process institutions virtually 'think', a constantly evolving procedure which accounts for the present and also (re)constructs the past to make it relevant to the present (Douglas, 1986:69).

A nursing home could be viewed as a place with unequal power relations. Residents are seen as vulnerable and dependent. Yet if we are to take a lead from Duckett and Fryer (1998) we should treat them 'as experts' – in the case of people with dementia, as experts in the experience of dementia. Residents' knowledge of dementia would in this way redress the balance in power relations. Power, control and knowledge are themes in work by Goffman and Foucault and it is these I discuss below in order to relate them to nursing homes.

Goffman, in fieldwork conducted in the 1950s, describes:

... a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life. Goffman, 1991: 11.

This place is what he calls a 'total institution', where collective living and activity is conducted 'to fulfil the official aims of the institution' (Goffman, 1991:17).

Within the total institution, Goffman says there is a very clear division between inmates who remain there all the time and staff who cross the boundaries to the outside when they are not working. Besides this differential in access to the outside, there is a divide in knowledge and power. 'Characteristically, the inmate is excluded from knowledge of the decisions taken regarding his fate' (Goffman, 1991:19). Foucault (1991) similarly is concerned with knowledge and specifically with the differential in power that occurs with the possession or absence of knowledge.

Total institutions referred to by Goffman are not nursing homes. They are places of confinement such as prisons and asylums in which privacy and personal possessions are often denied or sparse. With their denial, inmates are also denied symbols of identity and selfhood from their previous and outside existence. People entering a new living environment have to adjust and recreate their identity. When this place is a total institution, they must do so in accordance with rules and regulations laid down. People entering a nursing home similarly go through a period of adjustment: when they are people with dementia they may be vulnerable, particularly if the environment does not allow the symbols of self and identity to accompany the move.

Savishinsky (1991) comments on the contradictory role of the nursing home:

... the home that could not be a home, and the medical facility that rarely restored people to health—derived from the fact that the institution was neither a proper home nor a hospital. Savishinsky, 1991: 248.

This contradiction is important for people with dementia, where there is little prospect of treatment or cure.

Henderson (1995) describes nursing homes as characterized by the 'Cult of Time and Task'. The result of training staff to a medical model focuses their time on 'bed and body care, at the expense of humanizing factors common to more time intensive, cognitive psychosocial care' (Henderson, 1995:46). These physical tasks show immediate and apparent care and

benefit to residents in contrast to the invisibility of psychosocial care (Henderson, 1995: 53). This emphasis on 'bed and body work' is one also taken up by Gubrium (1997: 123-157).

How staff attitudes are influenced by training in the medical model is also demonstrated by McLean and Perkinson (1995). The head nurse in this study sees dementia as a diseased brain and demanding family members wishing to improve their relative's quality of life as having unrealistic expectations:

The head nurse's fatalistic disease model and pessimistic assumption about the value of environmental manipulation shaped the priorities she outlined in her hierarchy of care. Since, according to this view, so little can be done to change the trajectory of disease, "good enough" nursing care for dementia should focus on basic custodial and medical needs. McLean and Perkinson, 1995: 141.

Bed and body care is, as in Henderson's study, the focus of attention in Lee-Treweek's discussion of the hidden work that occurs in the bedrooms of nursing homes. She describes how a culture has developed to cope with the 'low paid, low status, dirty, physically backbreaking and tiring' (Lee-Treweek, 1998: 234) work. Abuse occurs backstage from the lounge where residents are presented in the public frontstage. This abuse consisted of ordering individuals around to facilitate efficient routine and a state of compliance from the resident, which clearly shows the use of power and control.

Another comment is presented on nursing home culture which shows power becoming a collusion involving family in the process:

Conflicts are played out between the nursing home as “quasi-hospital” and as “home”. The autonomy of the individual is pitted at times against powerful staff members, concerned family members, and the constraints of a bureaucratic institution. Shield, 1995: 124.

There does, in fact, seem little opportunity for autonomy of residents. Individuality also becomes subservient to the convenience of the group of people in the nursing home. Even when interests conflict individuals may be expected to remain under the control of the limited staff members. This is highlighted by Goffman’s description:

... under conditions where one person’s infraction is likely to stand out in relief against the visible constantly examined compliance of the others. Goffman, 1991: 18.

Infractions are thus easily detected by organization of ‘blocks’ of people in this way. As Foucault (1991) also pointed out, this ensures surveillance without the need for skilled workers.

The result of this nursing home culture upon residents is one of complying to rules ‘for their own good’. As Berger (1991) comments:

Identity comes with conduct and conduct occurs in response to specific social situations. Berger, 1991: 119.

Thus, in this way, the identity of residents is shaped by the specific social situation that arises from this nursing home culture. This culture can disable in the same way as disability studies have shown occurs for impaired people (Corker and French, 1999). Part of this is infantilization and excess disability.

Infantilization (Lyman, 1993; Hockey and James, 1993) and excess disability (Sabat, 1994) occur in the interest of efficiency within nursing

homes, and family members appear to collude in power relations to control individuals. The older person becomes more dependent as a result of these practices. Infantilization reduces them to childlike status. Power is held by those with knowledge and so they, rather than those with first hand knowledge, are seen as the experts. Rules are often enforced by this power imbalance and these are the focus of the attention now.

Rules and resistance

In discussion of people with dementia, Blaikie (1999) comments on their treatment objectification, labelling, infantilizing and stigmatising, and how they may cope with this. He speculates on whether resistance against their treatment occurs:

While 'confusion' implies failure to communicate, it may sometimes be a surface manifestation of a coping mechanism by which the older person willingly withdraws into subjective control of their own status passage. Blaikie, 1999: 194.

This willing withdrawal has been described in disengagement theory (Cumming and Henry, 1961) which amounts to:

... decreased interaction between the ageing person and others in the social system. Cumming and Henry, 1961: 14.

Until recently it was thought to be associated with ceasing to be in full time employment and signalled a progression towards decline. But, there is an underlying implication in the comment by Blaikie, that people with dementia may, contrary to appearances, be able to rationalise and actively offer resistance to their circumstances.

Resistance to conformity can be seen as a coping strategy and as a means of countering oppression and undermining power and control. Cohen and Taylor (1998) offer an explanation of resistance through distancing from reality. Boredom and routines can be distanced only after a self-consciousness of them has been achieved and set aside (Cohen and Taylor, 1998: 55).

People with dementia living in a nursing home are denied many of the escape routes from everyday life achieved through mental mapping, games, holidays and mass culture suggested by Cohen and Taylor. Open rule-breaking, then, may be more of an option for these people and also serve as a public declaration of resistance to nursing home rules.

Cohen and Taylor (1998) suggest three metaphors in use in accommodating reality: feeling at home, burden, and life as a prison. 'To be 'at home' with reality is to experience it as non-problematic' (Cohen and Taylor, 1998: 213). Burden is experienced when we perceive the world as 'highly oppressive and restrictive' (Cohen and Taylor, 1998: 213). But, their argument focuses around the life as a prison metaphor:

We are locked into a prison created either by ourselves or by others, by routine or by self-consciousness. We are trapped and want out.
Cohen and Taylor, 1998: 214.

This may be very close to the reality for some people with dementia living in a nursing home: resistance may be their way of coping with it.

Extreme approaches to social control create situations where resistance is likely. One such approach is that occurring in prison. Encouraging prisoners to participate in a programme of 'Cognitive Self-Change' was rewarded with sentence reduction (Fox, 2001). This incentive recruited participants who could benefit from feigned self-reform. Resistance took different forms:

... some selves are constructed to suit the institutional preference for right-thinking, nonviolent individuals. Some resist to the point of becoming more angry and violent. And some - the "expedient confessors," for example - may superficially comply, while trying to sustain their sense of an unchanged, inner self that they have lived by all along.
Fox, 2001: 191.

Thus, many approaches can result in the same resistance to social control. This is a point also made by Foucault (1980). He says that 'there are no relations of power without resistances' (Foucault, 1980: 142). Power relations are not only in the form of 'prohibition and punishment' but take multiple forms, being interwoven with relations of 'production', 'kinship', 'family' and 'sexuality'. Power is strategic and resistances are

... effective because they are formed right at the point where relations of power are exercised ... resistance is multiple and can be integrated in global strategies. Foucault, 1980: 142.

This is an important illustration because it shows resistance as strategic, as taking many forms, and operating at micro and macro levels; in fact, wherever there is power.

Evidence of resistance to power and rules is also presented by Bethal (1992) at a Japanese institution for the elderly. This is an environment of 'cultural construct imposed upon strangers' (Bethal, 1992: 123) with a

structure of rules and regularity designed more for the smooth running of the institution than the comfort of residents:

Many residents have difficulty adapting to their new lives ... They realize their powerlessness to make their own decisions ... of daily life. Bethal, 1992: 123.

This loss of autonomy is resisted by some residents through 'ingenious strategies to maintain a modicum of freedom' (Bethal, 1992: 124). Residents learn the tolerance levels of each staff member and what rules may be stretched with each. They devise ways, through joint collaboration, to overcome restrictions to drinking alcohol and going out of the institution after curfew hours. 'In their own networks, the ones who successfully evade the rules become heroes and popular figures' (Bethal, 1992: 125).

For vulnerable people living in nursing homes it may be difficult to operate these forms of resistance. Institutional surveillance, and conformity to rules, could account for many older people, including some with dementia, choosing to live independently, and why others often cannot fight against the rules that regulate them. *The Lady in the Van* (Bennett, 1994) only accepted institutional help after living for 15 years in a van in the garden of Alan Bennett. She went off to the day centre where she had been promised a bath, clean clothes and a comfortable bed. Bennett fantasised about visiting her there with flowers. However, after the company and clean up she returned to her van later that day and died during the night in the place of her choice. Reflecting on her last days:

... the doctor who pronounced Miss Shepherd dead said that she had known other deaths in similar circumstances; that it was not (as I had facetiously wondered) the bath that had killed her but that to allow herself to

be washed and put into clean clothes was both a preparation and an acknowledgement that death was in the offing. Bennett, 1994: 88.

The Lady in the Van thus kept control of her life to the end and exercised what must be the ultimate resistance.

Another example of how important independence can be is that of a homeless man. Keeping contact with, but disguising his circumstances from his children, he said:

“If they knew that I’m homeless they’d want me to stay with them ... I pretend that I have a flat ... they have their own lives to lead; I do not want to impose”. Crane, 1999: 81.

Yet more examples abound in Stephen’s (1976) ethnography of elderly tenants in a slum hotel. It is a study of older people who have chosen to live in a large slum hotel, in an American inner city. The hotel was at its best in the 1920s. Of the 524 rooms, 108 were rented to older people, whose length of residence ranged from two to 51 years. It is considered by tenants to be ‘one of your better low-class hotels’ (Stephens, 1976 :7).

Living in the hotel allows freedom over daily living. Choices can be made about when to eat and sleep and there is no housework to do. Some of the tenants have families or a home but live in the hotel for the freedom from chores and the independence and ‘to be with your own kind’ (Stephens, 1976: 8). Privacy is valued and company is available when wanted. Tenants also value the freedom to indulge in behaviours unacceptable to their families such as excessive drinking and associating with prostitutes.

The tenants are unanimously hostile and suspicious toward nursing homes. To these fiercely independent people, nursing homes represent the loss of autonomy they are determined to avoid. Stephens, 1976: 11.

In order to survive in the hostile, deprived, inner city area these tenants keep themselves to themselves, a sort of 'nonresponse' which can classify older people as regressive, passive and incompetent from a different perspective or in Stephen's words 'from the "other side"' (Stephens, 1976: 95).

These tenants emphasise the importance of being with 'your own kind' (Stephens, 1976: 8). This could also have implications for people with dementia living in nursing homes. Living with dementia can be disabling and fraught with problems in negotiating everyday life if others do not understand and empathise. Living in a nursing home where all residents have dementia should in theory remove the disabling effect of the condition.

Resistance is a strategy for coping with everyday life for most people and an indication of active participation. For vulnerable people this may be more difficult to employ. When this is so, others may be in a position to help the coping process in much the same way as Kitwood and Post both advocate, through the maintenance of personhood. However, every effort should be made to ensure that the person that is maintained is the one of individual's own choosing; to give voice to that person rather than speaking ourselves. Furthermore, we can reduce the disabling effect of the condition

for people with dementia, by putting the onus more on ourselves to adjust to dementia conditions.

Conclusion

Images of ageing and of dementia have variously been shown as being negative in popular culture and early dementia research. A huge influence on this has been the medical model that has dominated dementia and disability research and formed the basis of the culture that exists in nursing homes. For older people, a 'mask of ageing' shrouds the disparity between these images and what is felt. Much of the negativity of dementia, as with disability, has emanated from the medical model. Disability studies evaluate this model, producing an alternative that dementia studies can learn from: the social model of disability. There are also shortfalls in this model, in failing to take account of individual experiences of impairments, the subjective is ignored and disability is again reduced to objectivity. Dementia studies could learn from this and seek, instead of developing a separate field, incorporation into mainstream sociology.

Taking account of subjectivity involves studying relationships, social support, personhood and hearing the voice of people with dementia which can contrast to negative images, and serve to critique the medical model. The medical model provides the basis for the culture of nursing homes, which is one of surveillance. Within nursing homes, rules are applied which infantilize residents and exert power and control over them. However,

resistance offers a form of escape, which demonstrates self-control, choice and active judgement. Recognition that people with dementia may be exercising this resistance also acknowledges active participation, and enables us to hear people's various voices.

In this chapter the person has been placed first by outlining theory relevant to the thesis and to social research on dementia. By careful attention to perspective and avoidance of previous negative areas of focus, voice can be given to the person with dementia. Gaining the subjective view and placing research participants within the same theoretical framework as any research participants is a means of doing this. The broad theoretical basis of this study will therefore be one appropriate to explore relationships within ethnography and this is outlined in Chapter 3.

Chapter 3: Everyday life in the social world

It has been shown in the last chapter that establishing appropriate means for social research on dementia requires a change in emphasis from previous research on dementia. Shifting away from models which consider disease, allows us to place the person first. By definition a sociological study draws attention to the social aspects of being a person. That my research participants also have dementia becomes almost incidental and secondary. For this reason theoretical considerations can be based upon what it is like to experience everyday life in the social world, alongside the experience of dementia.

The theories of everyday life that I wish to apply to this study, are those that have been used to consider how any people make sense of their social world. According to Douglas, the only way to understand the social meanings of social actions is by an analysis of everyday life (1971:3). He says that all sociology starts with this, though it has often been denied. The reason is that everyday life sociology is so much taken for granted that it is sometimes recognised only at a subconscious level. However, to gain an understanding of the taken for granted, it is necessary to learn of the value systems and categorization taking place in everyday life. It is a 'unified approach to the study of social interaction' (Adler *et al*, 1987: 217). Analysis of this sort being applied to people who have dementia has, to date, been restricted. I should like to argue that because I am considering

the person behind the disease, it is an appropriate theoretical basis for this study.

There are a number of aspects of everyday life that I should like to highlight because they have relevance for the understanding of this study. Firstly, I should like to discuss a fundamental element of symbolic interactionism; that of symbolism, and how shared symbols enable understanding and communication. Following from this a discussion of form and ritual will serve to illustrate how understanding of meaning in interactions goes beyond words and language. With a basic level of understanding between individuals gained via language it can be seen that interactions are also staged to present particular images, strategies and definitions. Interaction becomes a matter of negotiation for positions of power and for purposes of inclusion and exclusion. In this way definitions occur which place some as subservient to others. This aids the definition and projection of self-images. It also enables categorization at a variety of levels, which in turn creates boundaries.

This study is concerned with investigating relationships and a key part of these is emotions. As with many aspects of interaction and everyday life sociologies, emotions are so much taken for granted that we often fail to acknowledge them. They are, however, an important element of relationships and may be particularly so for people who are thought to have a disease affecting the mind and rationality. As many of the sociological models presented here make only cursory mention of emotions, pertinent

areas emerging out of the sociology of emotions will be highlighted, to redress the balance.

Shared symbols in relationships

Symbols, socialisation, mind and self, constitute the theory of symbolic interactionism. As a micro sociology it displays how individuals interact in everyday life. Many aspects of symbolic interactionism are useful to provide a theoretical framework for this study and show the importance of symbolism for relationships.

There are three premises of symbolic interactionism. For Blumer, 'human beings act toward things on the basis of the meanings that the things have for them' and:

... the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows ... these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters.
Blumer, 1986: 2.

So, people create and interpret a shared meaning through interaction with others and constantly reassess this to take account of new and changing situations. Social interaction is often taken for granted and given little significance. Blumer says that symbolic interactionism, through examining the taken for granted, considers social interaction to be important as 'a process that forms human conduct' (Blumer, 1986: 8). This places the root images of action, interaction and constructed objects at the centre of a symbolic interactionist framework of analysis (Blumer, 1986: 6).

This is an interesting theoretical starting point in trying to gain an understanding of the world for someone who has dementia. Interaction with others can often be impaired for people with dementia: the words for objects can also often be lost or confused. Does this mean that shared meaning is also lost? When people who have dementia have been talked about from the disease model perspective this would most certainly have been the case. However, in placing the person first we may dispel this assumption. As with learning a foreign language more may be understood than can be expressed through words.

Blumer's symbolic interactionism drew upon, if it did not develop out of, Mead's earlier work. Mead's particular concerns were with the self and the mind. It is not an isolated individual but a social self that is discussed, one who uses symbols and gestures that have meanings shared with others. The self is thus one involved in thinking which is 'an inner conversation' (Mead, 1967: 141). This is a conversation of gestures as if presented to an outside audience and so is a part of social intercourse. For Mead, the self derives both from these inner conversations and those conducted with other people.

What the society is, whether we are living with people of the present, people of our own imaginations, people of the past, varies, of course, with different individuals. Mead, 1967: 143.

This may be particularly so for people who have dementia. People with dementia sometimes do not recognise people they have known most of their lives. They may believe that a casual acquaintance is someone more significant. They may also believe they see someone regularly who has

been dead for some time. Within the disease model these factors are seen as strange and problematic, yet for Mead they are clearly elements of interaction.

The meanings of symbols are learnt in relationships, and become shared symbols, and a means of understanding other people. Once the meanings are learnt, they form the basis of communication and thinking. Without them, understanding between those engaged in interactions, or for those engaged in thought, would not be possible (Mead, 1967: 146).

It may be easy to suppose that symbols refer only to naming of objects in order to have shared meanings. But by following customary gestures and actions, social cues are given out which allow definition of the situation. This is done almost automatically for familiar situations (Strauss, 1997: 48-49). Social cues also aid the flow of interaction through allowing an understanding of shared conventions in the interaction order.

Mead says that we always think in symbols which we assume mean the same to other people (Mead, 1967: 147). Whilst we may share the symbol, the meaning may vary between people and between the same people at different times. If the people with whom we are interacting also have dementia, forgotten words or descriptions for objects may cause additional disparity. Mead says that the symbol 'must have the sort of universality to any person who finds himself in the same situation' (Mead, 1967: 149).

Drawing on the example of a blind person, Mead explains this further by saying:

... it was not until she could get into communication with other persons through symbols which could arouse in herself the responses they arouse in other people that she could get what we term a mental content, or a self.
Mead, 1967: 149.

Just as the blind person initially failed to be aroused in the same way as seeing people, the person who has dementia may not be aroused in the same way as someone who does not and this may cause misunderstandings and confusion in communication. This situation may be similar to that of the 'stranger' discussed by Schutz (1971) from a phenomenological perspective.

By contrasting the situation of the stranger, Schutz (1971) shows that in everyday life there is an assumption of shared understanding and perspective of those he calls the 'in-group':

Any member born or reared within the group accepts the ready-made standardized scheme of the cultural pattern handed down ... as an unquestioned and unquestionable guide in all the situations which normally occur within the social world. Schutz, 1971: 28.

For phenomenologists, shared understanding extends beyond gestures and symbols to encompass what may be typically so, in typifications. We have a stock of knowledge, some of which is shared with others in language. We use typifications with structures defining whom we share knowledge with through interaction in everyday life. Those we most closely associate with are consociates whom we know intimately in the present. We also have contact with contemporaries who live at the same time as us

and may become consociates. Typifications may be understood by what has been passed from predecessors who come before us and we may pass down to successors who follow us. This structure may be important for people with dementia and how they conduct relationships with people of different time periods (Schutz, 1973).

Resulting from these expectations of how everyday life will be, is a reality or province of meaning, which Schutz says is subjective and finite (Schutz, 1973: 207). But because it is taken for granted and made up of 'a series of common-sense constructs . . . pre-selected and pre-interpreted' (Schutz, 1973: 59), it is experienced as the reality. This province of meaning will only be recognised as finite and be replaced by another when something causes us to view the world through a new reality (Schutz, 1973: 231).

Shared symbols and typifications are an important means for us to understand each other in interactions. They constitute the basis for language and communication and how we view contextual reality. They provide the subjective interpretation of everyday life.

Within symbolic interaction, meanings are formed. Objects are the products of symbolic interaction and may have different meanings for individuals, but:

The meaning of objects for a person arises fundamentally out of the way they are defined to him by others with whom he interacts.
Blumer, 1986: 11.

Thus, if the meaning is gained by talking to others within a particular environment, then an understanding of it can only be gained by including contextual consideration. Context is central to the ethnomethodological concern of indexicality, which is to be discussed later.

Nursing homes and dementia both present specific situations regarding language usage which illustrate the specifics of their shared symbols. Nursing homes are entrenched in medical terminology not necessarily used in everyday language outside that environment. People with dementia often forget names of objects or other words. It is still possible, without a full vocabulary of shared symbols, for a general understanding of meanings to be shared. This will be demonstrated in the discussion of form and ritual.

Form and ritual

It is clear when ritual is examined in the context of primitive cultures that, among other things, it is used to solve problems arising out of anomalous situations. For instance, tribal rituals with strong use of symbolism have been used to solve gynaecological disorders and restore the balance between matriliney and marriage (Turner, 1995). The symbolism used in gestures, time, space and objects stands 'for something other than itself' (Turner, 1995: 15) and allows ills to be ritually corrected, a correction it is hoped will be mirrored in reality.

In primitive cultures symbolism encompasses the total universe and gives meaning. In modern cultures, symbolism is still used but is more fragmented because of variations in contextual situations (Douglas, 1994: 70). In both types of culture a set of assumptions controls experience through ritual symbolism and this is the purpose of rituals. They:

... enact the form of social relations and in giving these relations visible expression they enable people to know their own society.
Douglas, 1994: 129.

Goffman is quite explicit about the ritual and form involved in interaction. This is not the ritual of ceremonies but involves the 'movements, looks and vocal sounds we make as an unintended by-product of speaking and listening' (Goffman, 1981: 2). They constitute 'gestural conventions' which follow familiar patterns. Interaction occurs within a 'participation framework' where those involved adopt 'appropriate conduct' and use words that 'are often not our own'. Who can speak is 'situationally circumscribed, in whose name words are spoken is certainly not' (Goffman, 1981: 3). This clearly places interaction as a technique beyond words, where ritual and form provide additional meaning which may complement or contradict what is said.

Following familiar patterns as straightforward as sequential patterning of the days of the week can have the 'effect of ritual' (Douglas, 1994: 66). The pattern of Tuesday following Monday produces a pattern that is a necessary part of the procedure of the regular ritual. This sort of patterning

through symbols 'condition experience' by their regular sequencing 'as one of their important functions' (Douglas, 1994: 66).

Meaning is gained not only from the content of interactions used, but additionally from their form. Social competence is maintained by following conventions of form. The significance of form for this study was only discovered as fieldwork was under way. Turn-taking and rituals upon departure, for instance, will be introduced in the analysis on interaction (Chapter 8).

Much of the useful theoretical background on form emerges out of ethnomethodology, which is the study of methods used to gain meaning in everyday life. Because the focus is upon methodological examination, close detail is investigated. This starts with a premise that everyday life must be challenged because it is taken for granted. Garfinkel (1967), well known for this disruptive technique, sought to reveal the methods people use to negotiate everyday life, by uncovering what is taken for granted. This is useful for this study, because I want to understand how people negotiate everyday life. Ethnomethodology also provides context for people's actions. We reference our previous experiences and knowledge and from these form rules, norms and terms with indexicality. This process gives context to a situation (Morris, 1977: 41).

It follows that having engaged in indexicality, this is referenced when the same context recurs. This allows form in interaction to be followed, which

both adds to the meaning and allows those involved to gloss over details (Cicourel, 1973: 109). Glossing provides a generalized view of a situation, without examination of unnecessary detail. When people may have lost some understanding of the situation, or of language, this may be an effective means of maintaining social competence and allowing interaction to continue.

Because ethnomethodology is concerned with methods to understand and make the everyday taken for granted meaningful, ethnomethodologists are interested in language and language usage. This may appear to be of little use in a study involving people who may experience some loss of language. However, the form of interaction is of interest for exploring relationships between people with dementia, and it is form that ethnomethodologists also gain meaning from.

Strategic interaction

If interactions consist of content and form, which together give the basis for shared meaning, then the way in which these are managed can be strategic. Expression frames the messages which pass between subject and observer (Goffman, 1970: 10).

Not only is the self presented in a way that projects a favourable image (Goffman, 1990), but the management of self becomes a part of the 'expression game'. These develop and change with evolving cues and observational instruments (Goffman, 1970: 27). When interests are shared

individuals become team players, or may be seduced into believing that they may be a teammate 'to whom strategic information (among other things) can be voluntarily entrusted' (Goffman, 1970: 37).

As part of the socialization process children learn from others through play. They play the role of significant others, such as mother, teacher, or policeman. They learn about their attitudes to them by playing their roles (Mead, 1967: 150). Once these roles are understood, and as the child gets older, they become involved in games with more players. In order to take his or her own role (s)he must appreciate what all these other players are doing. Gaining a sense of this then gives 'an "other" which is an organization of the attitudes of those involved in the same process.' This group, which may consist of a team or a whole community, is the generalized other (Mead, 1967: 154).

Following Mead's (1967) argument that when individuals consider taking action they first imagine the consequences for others and their likely response and modify their actions accordingly, Goffman says:

Now when the courses of action, actual and imagined, consist of assessment and response to assessment we find ourselves dealing with virtual or tacit moves in an expression game. The observer imagines the likely consequence of the subject discovering that he is being assessed, and attempts to offset the likely control of impression before it has had a chance to occur. Goffman, 1970: 47.

Such rapid adjustments to impression management, as suggested by Goffman, require and demonstrate proficient usage of language and other

forms of expression. Such proficiency also indicates social competence and active participation, both of which I wish to investigate in this study.

Strategic interaction for Goffman can be seen as manipulative and operating predominantly in the interests of the subject. Yet strategy can also be employed co-operatively, even when those co-operating may not necessarily be teammates. Lofland suggests that in public settings individuals do manage themselves to project a favourable image to others, but additionally they offer support to others. In this way 'social life may be viewed as a kind of social bargain, a whispered enjoiner to let us all protect each other so we can carry on the business of living' (Lofland, L, 1978: 44). This social bargain may apply to those we know or to strangers. However, whilst this may at first appear as altruistic generosity, Lofland qualifies the circumstance where failure to do so would prove dangerous. This mutual support also has implications for common symbols in the social system:

We cannot tear at the other too much because to do so is to threaten the meaning system which supports us both. Lofland, L, 1978: 45.

Strategic interaction can then be seen as manipulative, designed to gain power over others and project favourable self-images. It can also be seen as co-operative between teammates with similar interests and between strangers. Yet, when we consider the social implications of failing to maintain the meaning system of shared symbols, then strangers must also at least become corroborators if not teammates.

Dramaturgy

The supportive roles of corroborators can become a matter of collusion within the dramaturgical analogy. Collusion occurs between co-actors and between performers and audience for perfection of the performance. This is considered the same for individuals or institutions:

Within the walls of a social establishment we find a team of performers who cooperate to present to an audience a given definition of the situation. This will include the conception of own team and of audience and assumptions concerning the ethos that is to be maintained by rules of politeness and decorum. Goffman, 1990: 231.

These rules of 'politeness and decorum' also have implications for the form of interactions. They suggest co-operation and compliance with an acceptable form which will help individuals present a suitable impression and appear competent in their performances.

Much of how we behave in public is in fact, subconscious because of following familiar conventions. As children being socialized, we learn etiquette, which becomes so much taken for granted that it is frequently performed without prior planning (Goffman, 1963). This taken for granted aspect of social interaction makes it worthy of further investigation.

Engaging in conscious or subconscious behaviour in interactions involves taking roles and this is a part of role theory (Goffman, 1972). As a particular role may be performed regularly a self-image is derived from it. Actors often make mistakes, dress inappropriately, forget a name and:

... a momentary discrepancy arises between what the individual anticipated being and what events imply he is. Goffman, 1972: 92.

Some roles may be enthusiastically embraced, there may be superficial engagement in the role, or there may be a withdrawal from the role or role distance. Goffman illustrates these levels of engagement in the role by how children behave on a merry-go-round. At age three, children are completely taken up in the role of riding on the merry-go-round (Goffman, 1972: 94). At age five, children riding the merry-go-round wish to demonstrate their competence by projecting a more relaxed image. At age seven, children find it difficult to play the role of merry-go-round rider with enjoyment. They show either bored facial expression or employ dare-devil tactics and in so doing distance themselves publicly from the role. Resistance, detachment and separation from the role is indicated,

... the individual is actually denying not the role but the virtual self that is implied in the role for all accepting performers. Goffman, 1972: 95.

It is worth noting that role distancing is just as much an act as engaging in a role. This role distancing, then, is also an important part of impression management and has implications for the image of self presented and also for the way the self is defined.

Differentials in power and labelling

In managing impressions and defining selves there are power differentials. Actors negotiate their positions, presenting a favourable self which is defined through role play and in relational and reflective terms to others. Co-operation ensures smooth interaction, suitable social cues and mutual

support in language, form and ritual. This collusion requires and aids social competence and active participation. However, as part of the strategy some people are placed in positions that are more powerful than others. This power can be used to define, label and exclude.

Exclusion can occur through inequality of power which allows some to be in a position to define others as subservient to them. The clearest and most widespread example of this references woman in relation to man. This sets the man as the superior subject and the woman as 'other'. It assumes a hierarchy where man is dominant and woman is subordinate. Man is set up in a privileged position to which woman is considered subsequent (de Beauvoir, 1988: 16).

This process of giving power to some to define others as subordinate is the basis of labelling. It has been prevalent with regard to mental illness in this context and is seen as 'a medicalization of deviance in order to maintain social control' (Ussher, 1991: 134).

Labelling involves subjective judgements which may cause some behaviour to be labelled as deviant for one individual whilst it is not for another. This phenomenon manifested prevalently in the seventeenth century Salem witch-scare (Bednarski, 1990) where accused witches were used as scapegoats and blamed for problems of instability in the puritan belief system. Those most readily labelled were initially of low status in the

community, but as moral panic set in, and problems failed to be resolved, lower classes also accused higher classes on the basis of difference.

The crucial point about labelling then, becomes treating those who threaten a value system as outsiders. In Becker's view this is based upon deviance as a failure to agree to rules:

... social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders. From this point of view, deviance is not a quality of the act the person commits, but rather a consequence of the application by others. . . The deviant is one to whom that label has successfully been applied; deviant behavior is behavior that people so label.
Becker, 1991: 9.

Becker makes a distinction between rule-breaking and deviance, with deviance being when there is a reaction from others and rule-breaking when there is not.

Deviance is not a quality that lies in behavior itself, but in the interaction between the person who commits an act and those who respond to it.
Becker, 1991: 14.

This may have particular relevance to this study for two reasons. Firstly, people have dementia and may have been labelled as such, and secondly, because residents are living in a nursing home environment with rules that they may or may not have agreed to. Deviance also serves the purpose of testing moral boundaries (Erikson, 1961). The act of deviance and the response to the rule-breaking element of it initiate reconsideration of the categorization that has caused the infraction to occur.

In interactionist terms labelling has further implications beyond the naming of a deviance, as it is seen in terms of creating a career of deviance.

Labelling is seen in terms of initiating the deviant career:

It is evident that the labelling which punctuates deviant careers does not have to be imposed by external agencies at all. Indeed many specific acts of rule-breaking are never seen or described by outsiders. Rock, 1991: 238.

It has been seen that those involved in interactions co-operate and mutually support each other: they collude and corroborate. Yet when labelling occurs, it may lead to a 'career' of deviance (Goffman, 1991). As part of the moral career of the mental patient, the labelled person sees conspiracy against him, taking place between his family and health professionals (Goffman, 1991: 125). This occurs in what Goffman terms the 'prepatient phase' of the career and is accompanied by feelings of 'abandonment, disloyalty, and embitterment'.

After hospitalisation, the biography of the labelled deviant is reconstructed retrospectively to take account of obvious indications of the deviance leading to the label. This aspect of the career may be relevant to people with dementia. Once the label of dementia has been applied all behaviour may be attributed to the condition regardless of personal characteristics and tendencies, and without setting them in context of the situation.

In my study, much of what Goffman describes may be more attributable to the setting of the hospital than the condition of mental illness. For instance, it is difficult to support self-identity when personal props are denied, and staff may actively discredit any patient construction of identity in favour of

supporting the label already placed upon them. Discredit often takes the form of 'mockery and sarcasm' and becomes a means of social control (Goffman, 1991: 152).

Definition of self through others

Within this environment of discredit to self-identity and reinforcement of a deviant label, it can become easier to conform to images presented. Vulnerable people, vulnerable by label, environment or disability, may gain more of their self-image from others than does someone without such disadvantage. This reflective image consists of three main elements:

... the imagination of our appearance to the other person; the imagination of his judgment of that appearance; and some sort of self-feeling, such as pride or mortification. Cooley, 1998: 164.

This 'looking-glass self' clearly relates to others and will be investigated further in the discussions on emotions (later in this chapter). It has relevance to the 'mask of age' (Hepworth, 1991), because it shows how self-image is acquired in relationships. This may be 'imagination of his judgement' or more directly in projected attitudes from others such as Goffman's 'mockery and sarcasm' (1991: 152). Yet, in the 'mask of age' there is a disparity in images of old age and self-feeling, and this points to a form of resistance to negative images presented.

Additionally, in a social world we not only imagine how we appear to others to gain a sense of self, but also, often define ourselves relatively, by

reference to others. This has been referred to as 'reference other orientation' (Kuwayama, 1994). A reference group can be one:

... whose presumed perspective is used by an actor as the frame of reference in the organization of his perceptual field. Shibutani, 1971: 132.

This reference group consists of an audience of real or imaginary people, who may be numerous or solitary and represent a clear or unclear category (Shibutani, 1971). The self may be defined by reference to the immediate (significant others), a generalized other, or a reference society (Kuwayama, 1994: 143). Competence in referencing of this sort would undoubtedly demonstrate active participation and social awareness.

This social awareness is reflective of the shared meanings gained in interactions which also give meaning to, and enable, thought about the self. Through varying roles the self is projected and formed, adjusting to different stages and reactions of significant and generalized others. As such, what emerges is not one self but 'multiplicities of self' consisting of the person's sense of self, the attributes of that person and the person that others take us to be (Harré, 1998: 177). How these multiplicities of self are presented to others is frequently through the use of narrative.

Narrating selves

People tell their life stories as a means of projecting an identity to an audience:

Narrators artfully pick and choose from what is experientially available to articulate their lives and experiences.
Holstein and Gubrium, 2000: 103.

Some of the previous articulation and memory for people with dementia may be lost: what they thus narrate may be more what they are reminded by others as being their story. In this way their past may be reinvented and the sense of self changed to that of a person who has dementia,

... constructing a version of the past with the retrospective knowledge that she had dementia. McColgan *et al*, 2000: 102.

Accounts are not fixed and can undergo a transformation (Strauss, 1997). Within this transformation there can be an altered narration of self which is not fixed for narrators whether with or without dementia:

A life or self described and heard as coherently relating why or what we are on one occasion may not come off in the same way on a different occasion. How a story is put together is sensitive to local understandings about how a story is composed. Holstein and Gubrium, 2000: 107.

Change in circumstances can initiate a retrospective reconstruction in relation to a new situation, such as occurs with married couples. Within marriage personal histories are redefined in order to relate them to the partnership (Berger and Kellner, 1972). Within the nursing home setting an acceptable narrative may be one that tallies with what has been reported by others as being the truth. Offspring may often have a view of their parent's life as conforming to acceptable norms for people of that age which may not be the truth or reality for that person. Because of the disabling aspect of dementia, people who have it may not be given the freedom to project the self or identity they wish.

Autobiography can also be described as narrative. 'It is just the story of my life as told by me, from my point of view ... is above all a narrative' (Harré, 1998: 142). Further the 'written tale is just one of the autobiographies that a person did tell or that they could have constructed' (Harré, 1998: 143). In this way, we can see that we have many narratives for different purposes and audiences, they may become more fixed or fluid in the telling. They are a way of constructing what we wish to project as the story of ourselves, at the particular point in time of their narration.

Life histories are often used therapeutically for older people and life story work for people who have dementia is common (for example Gibson, 1994; 1997; Murphy and Moyes, 1997). Through the narration of their lives people can construct, and retrospectively reconstruct, images of self suitable for the audience and situation. They also present contextual information about how the self is formed:

... individuals' experience reflect the structural facts which impinged upon them and moulded or constrained their experiences and actions.
Dex, 1991: 2.

In turn this shows what is taken for granted and part of everyday life for individuals and the group.

Boundary definition

How we classify others and ourselves is a part of gaining identity. In relation to the self this is usually thought to be individual, though it has been seen to occur in relationships with others as well. Classification can be a collective process and this involves the boundaries between ourselves

and others. Self definition is reflective and reflexive of value systems, the taken for granted, and how individuals make sense of and categorize what they encounter in everyday life. Within the theoretical framework that I am using symbolism is an important element. This symbolism is extended to boundaries and how people categorize to make sense of the world in which they live:

The idea of society is a powerful image. It is potent in its own right to control or stir men to action. This image has form; it has external boundaries, margins, internal structure.
Douglas, 1994: 115.

External boundaries and internal structure suggest a pushing and pulling of boundary definition from outside and in. Just as images of self respond to these dynamics, so too will the boundaries pertaining to the setting, the community in which it is situated and the wider social system.

Amounting to a form of social control, gossip and scandal become a means of defining insiders and outsiders. Who does the gossiping, who it is about and who it is to, define all of these actors as insiders. Outsiders cannot join in gossip, which helps define them as outside, maintains the boundaries and social order, and in sum is exclusionary. In this way the 'values of the group are clearly asserted in gossip and scandal' (Gluckman, 1963: 313).

Another form of social control is that of conformity, which operates by the fear of exclusion. Insider status is at risk by nonconformity, as is the possibility of losing face. When the boundaries of conformity and nonconformity are clearly drawn there is also a high potential for transgression. Valentine is describing Japan, whose society has a strong

'belief in conformity and homogeneity' which in turn produces outsiders who 'may in turn promote the insistency with which the conformist claims are made' (Valentine, 1997: 100).

Japanese society is not unique in promoting conformity and nursing homes may be an example of an environment where group conformity is encouraged. Individuals may use conformity in a calculated manner of self-presentation to mask their difference.

Conformity and nonconformity have to be seen as relative and pertaining to social context. Both will align you with some and distinguish you from others. Valentine, 1997: 108-109.

I would contend that conformity can in this way be used strategically, both by the institution as a means of control through the threat of exclusion and by individuals within the group as a means of ensuring their inclusion.

Boundaries enclose elements which may, for certain purposes and in certain respects, be considered to be more like each other than they are different. But they also mark off these elements from those which differ. Cohen, 1995: 14.

Through categorization and the division that this creates symbols give the capacity to make meaning. But, whilst the symbol may be shared, the meaning may differ according to perspective and interpretation. The making of a symbolic representation is accompanied by boundaries which surround it. Cohen's example of this process is of the symbolic construction of community.

Wallman (1986) concentrates her discussion on household boundaries. Whilst there is a household identity for those contained within the

boundaries as seen by outsiders, Wallman argues this may differ significantly from the perception by individuals from inside (Wallman, 1986: 63). The boundaries are fluid, constantly adjusting to evolving situations in everyday life, and redefined from outside and within. The household boundaries could also be likened to those of a nursing home. In this way, Cooley's Looking Glass Self now becomes another useful image for analysing the forces at play in identity of units and individuals.

Within a nursing home, as has been discussed earlier, residents may be strongly influenced by those with whom they have regular contact. Care Assistants, as those most regularly and intimately involved with residents, will undoubtedly be in a position to project a looking glass self to residents. This same process may be in operation at nursing home level. The nursing home, like the individual resident, is a bounded unit with insiders, outsiders and those from outside who come within (more frequently than insiders going out). It is also a bounded unit within a community and within a wider society. As such, it is subjected to social and public policy pressures which are capable of projecting an image on to the establishment. This image is responded to in line with regulations and a nursing home self-image is presented to the outside.

The nursing home environment could be thought to consist of a community. In my study the full-time community consists of people with dementia. At all times they are joined by others who are the employees of the establishment and cross the boundaries of the nursing home each day to

work and home again. Part of the community is thus transient, between inside and outside, whilst residents remain largely inside. Others are more temporary, visitors who cross from outside where they are insiders to inside where they become outsiders.

This boundary crossing is also seen in ethnic communities contained within a more dominant societal boundary. Gypsy women, for instance, regularly leave their territory to 'knock on doors of unknown men' (Okely, 1975: 59). They buy, sell and tell fortunes for income. Leaving behind the rules under which they behave in their own community and adapting in line with expectations in the community in which they trade, they then traverse the boundary again at night and revert to gypsy norms.

This transformation when crossing to the outside is temporary for gypsy women. Within the boundary of the gypsy camp they follow rules, customs and beliefs quite different from those outside:

The Gypsies are under constant pressure from the dominant society to become assimilated. Okely, 1992: 77.

This assimilation would be on the terms of the dominant society. It amounts to conformity which may in Valentine's (1997) terms be exclusionary, strategic and a further example of social control.

This relationship between inside and outside is tenuous and the example of the gypsy camp is perhaps mirrored by nursing homes:

Too great a value emphasis on rationality and memory . . . wrongly excludes people with dementia from the sphere of human dignity and respect. Post, 1995: 2.

The dominant culture struggles to know what to do about people not fitting the rationality value and people with dementia rather than being treated as complete outsiders stay on the boundaries. As such they represent a threat and potential danger to be controlled. Additionally, I would contend that this boundary situation presents a situation that is also potentially open to resistance.

There is a sense in which association and close contact with boundaries can imply danger, even when not anomalous through defying classification. This can also be the case when regular boundary crossing is necessary. It may be so for staff coming into contact with people on the boundaries. Luske (1990), for instance, found that staff working in a psychiatric ward, at times emphasised difference to address their own fears about 'sanity' (Luske, 1990: 85). However, they were so used to looking for signs of and constructing psychosis for patients, that they also recognised psychotic symptoms in themselves (Luske, 1990: 112). They crossed the boundaries between the inside of the ward and the outside each time they worked. The danger of this practice is often guarded against through symbolic ritual such as carrying the bride across the threshold of her new home, a move which symbolises a transition to married life (van Gennep, 1965: 20).

Similarly, Stevens (1997) found that volunteers working with migrant day labourers who were defined as marginalized members of society, could not

be protected from the ambiguity of the situation. Day labourers are considered ambiguous and marginal because of their transience. This causes the area where they gather, and the people within it, to be considered as ambiguous. By association, volunteers therefore 'lose many of their mainstream qualities' and are considered as outsiders:

Thus, the volunteers and their clients create a liminal social category for those who have "dropped" through traditional family and professional roles. Stevens, 1997: 17.

Classification which causes ambiguities often creates dichotomous opposites such as inside and outside; frontstage and backstage; self and other. They result in varying levels of formality or intimacy according to the circumstances and audience, and are not fixed but constantly changing. The way that these may adjust and compensate for changing situations have been described as 'three situational domains' (Lebra, 1982). A situation can be characterized in terms of inside or outside and front, 'which is exposed to public attention', or back, which 'is hidden from the public eye' (Lebra, 1982: 112). They can occur together in three combinations to produce intimate, ritualistic or anomic domains.

Intimate behaviour arises out of the combination of inside and back, and is characterized by unity, spontaneity and emotional attachment. It is 'a situational boundary, not a relationship, (which) permits such intimate behavior' (Lebra, 1982: 117). A ritual situation will arise when outside and front occur together, producing tense posture, formal gestures and polite conversation. As with Goffman's descriptions of presentation of the self, Lebra's ritual behaviour in Japanese society is concerned with not wishing

to lose face. This can best be achieved by avoiding risky situations and hiding emotions behind ritual. The final situational domain, the anomic, takes place when outside and back occur together. This category is residual, and behaviour patterns are not as clearly defined as with intimate and ritual domains. It can arise in unfamiliar circumstances and result in disregard for strangers which causes them to be, for instance, knocked over in the rush for a train (Lebra, 1982: 131).

Situations, audiences and situational domains are constantly subject to variance. If a situation occurs where both ritual and intimate behaviours are required, rather than mixing the behaviours they are usually performed sequentially. Ritual greeting may be followed by intimacy before a return to formality according to the situation:

Situational mixture is avoided by giving priority to one situation over another, by ignoring one and dealing with another, or by sequentially arranging one situation after another.
Lebra, 1982: 136.

The care in doing this highlights the ambiguities arising by not observing the boundaries and the danger present at the point of crossing the threshold.

Van Gennep describes this point of carrying the bride across the threshold as liminal, and liminality is often a characteristic of ambiguity and boundary crossing. 'Liminal entities are neither here nor there; they are betwixt and between' (Turner, 1995: 95). The ambiguities of the situation or people caught in transition, or defying classification, are highlighted through rich

ritual symbolism. They are often initiates in rites of passage represented as possessing nothing:

Their behavior is normally passive or humble; they must obey their instructors implicitly, and accept arbitrary punishment without complaint. Turner, 1995: 95.

Immersion in humility is thought to channel power to a high status, guided by representatives of the community (Turner, 1995: 106).

Obedience and humility may also be witnessed in institutional settings as are other characteristics of liminality, 'submissiveness and silence'. Liminal entities:

... submit to an authority that is nothing less than that of the total community. This community is the repository of the whole gamut of the culture's values, norms, attitudes, sentiments, and relationships. Turner, 1995: 103.

As when people are labelled, strong elements of control appear to accompany the ritual associated with liminality, the fear is of a threat to values. When people have dementia, in a culture structured upon valuing the mind, they too may appear to threaten.

The liminal phase in rites of passage is accompanied by a long period of seclusion before ritual acceptance to a new status. Though not all people who have dementia are moved into residential care with others in a similar state, the common practice of doing so could be explained by considering them to be in a liminal state, waiting for acceptance to a new status. In many cultures close proximity to birth and death are liminal states often enacted ritualistically by initiates. In modern cultures, ritual accompanies

naming a child, and funerals for the dead also signify the ambiguity of these transitional states. So, people who have dementia could also be considered to have liminal qualities associated to their proximity to death. This may be particularly so when they are also in old age.

Liminality requires a certain amount of self control to be relinquished:

It seems that if a person has no place in the social system and is therefore a marginal being, all precaution against danger must come from others. He cannot help his abnormal situation. Douglas, 1994: 98.

Precautions against danger coming from others may be more in the interests of social order and the community than the liminal entity. This may be the case for people in institutional care, and justification of this can often be heard in a paternalistic discourse of protection and care, one which can infantilize (Hockey and James, 1993: 3; Lyman, 1993: 68).

Van Gennep's description of initiates in rites of passage struck me as having similar properties to the stereotypical ways in which people who have dementia are perceived. This is a conclusion that Sweeting and Gilhooly (1997) also reached when they suggested that people with dementia had 'suffered' a form of social death (Sweeting and Gilhooly, 1997: 99). This amounts to withdrawal from life prior to biological death. Adjustment from lives centred on the workplace to a 'socially impoverished future' (Blaikie, 1999: 177) was also the basis of theory suggesting deliberate withdrawal from society as a form of disengagement for older people.

Sociology of emotions

Lebra's intimate situational domain arising from inside, backstage situations, is the domain of emotions. So much a part of the private sphere, emotions often remain hidden from theory, taken for granted, yet restricted in explicit discussion. Mead mentions emotional attitudes and emotional responses (Mead, 1967: 147), and similarly Cooley describes our reactions to how we imagine others see us as 'some sort of self-feeling, such as pride or mortification' (Cooley, 1998: 164). Goffman appears to take for granted that emotions are involved in the presentation of self (Goffman, 1990), and yet they become a limiting factor as they need to be controlled so that cues are not given out in expression games (Goffman, 1970: 31).

Goffman's presentation is, however, only a part of the 'emotional system' in which Hochschild (1983) identifies three discourses separately concerning labour, display and emotion. The discourse of labour involves communication, display relates to presentation, whilst the third discourse is concerned with identifying what constitutes an emotion.

Different disciplines have focused upon aspects of emotions, science upon physiological changes occurring in the body and philosophy upon cognitive change and control (Gubrium, 1989; Harré, 1986; Lupton, 1998). A sociological view can acknowledge physiological changes in the body in

accordance with culturally interpreted actions, responses and feelings. For instance, a social constructionist perspective:

... opens up the possibility that many emotions can exist only in the reciprocal exchanges of a social encounter. Harré, 1986: 5.

This points to the cultural influences which shape interpretations through shared symbols to create an emotional reality. In this sense, emotion is seen as active, something we do (Hochschild, 1983: 27) and intentional (Harré, 1986: 8). Language usage often illustrates action, intention and source of emotion. We manage emotions, do emotion work (Hochschild, 1983), feel anger at a situation (Harré, 1986: 8), and talk in the first person to say what "I" feel (Hepworth, 1998: 173), and this is set in referential and contextual terms:

Awe, love, anger and envy tell of a self vis-à-vis a situation. When we reflect on feeling we reflect on this sense of "from where I am". Hochschild, 1983: 30-31.

Reflection involves emotional memory which Mead (1967) and Hochschild both mention in the context of how they may intensify the depth of feeling and produce an 'emotional attitude'. The:

... process of finding the expression in language which will call out the emotion once had is more easily accomplished when one is dealing with the memory of it. Mead, 1967: 148.

Thus, whilst emotions may be considered to be deeply personal and often private, they are in this view as much a part of symbolic interaction as conversation is, be it shared with others or internalised in thought.

In a psychological study of dementia, Mills suggests that emotions are so significant as to 'have a profound effect on memory in dementia' (Mills,

1998: 174), even when cognitive impairment is apparent. I would argue that if this should be the case, then it is because of the social element of emotional memory and the context in which it is recalled.

Emotional memory has significance for older people. They are seen to be more likely to experience nostalgia than younger people. This belief leads to a labelling of older people as 'other' and a distinctive group. This is the view of Davis (1979) discussed by Hepworth:

If, as Davis argues, the attribution of distinctive emotions to ages and stages of life is a socially determined method of maintaining boundaries between groups of individuals, it becomes much easier to make sense of the tensions existing between public images and subjective experiences. Hepworth, 1998: 179.

These tensions between public images and subjective experience resound both of Hepworth's (1991) 'mask of age' and of tensions caused by presentation in Hochschild's (1983) study.

An element of emotions attributed mainly to women is emotion work, an unseen effort of many jobs, which requires control of self and emotions. Through studying airline stewardesses, Hochschild found that by tending to others' needs and projecting a company image, staff had to put aside their own emotional needs. Through 'surface acting' of emotions they altered their outward appearance, managing their feelings to 'actively try to change a preexisting emotional state' (Hochschild, 1983: 219).

Commercialization of human feeling (Hochschild, 1983), to make airline passengers feel good, at the expense of staff's own feelings, amounts to

institutional control. Rules and customs are applied which require the replacement of what staff are feeling with what the institution wishes them to feel. James defines emotional labour as that:

... involved in dealing with other people's feelings, a core component of which is the regulation of emotions. James, 1987: 15.

There may be an element of this happening in nursing homes, not only to staff but also to residents. In a residential home ethnography, emotion work with 'the confused' involved staff in 'cajoling, cuddling and kind words' (Lee-Treweek, 1996: 128). Care assistants thought that the emotions of residents needed to be balanced, controlled and monitored (Lee-Treweek, 1996: 123). Beyond institutional control, we also engage in what Hochschild calls 'deep acting' in order to evoke appropriate feelings for a situation and comply with cultural expectations. This is done:

... in complete privacy, without audience or stage . . . Sometimes we try to stir up a feeling we wish we had, and at other times we try to block or weaken a feeling we wish we did not have. Hochschild, 1983: 43.

This may also be the way that we prepare ourselves for rituals such as funerals, weddings and formal meetings, so that the appropriate feelings for the situation are projected.

The way that many flight attendants dealt with conflicts of emotional interests in their jobs was to detach from the emotions they were showing. They likened it to a technique where self separated from role, emotions were numbed and an estrangement from display occurred (Hochschild, 1983: 188-9). Similarly, in a psychiatric ward, a member of staff used 'avoiding techniques' for coping with emotional pain which put a 'distance

between his and the residents' psychological suffering' (Luske, 1990: 60). Production of a 'false self', in this way, makes the boundaries unclear, and is potentially dangerous, with a possibility of losing a sense of what is really being felt (Hochschild, 1983: 198).

This distinction between what appears to be felt emotionally and what is really being felt is sometimes described in terms of belonging to the outer self projecting a public front, and the inner self that remains essentially private and hidden. The real emotion is characterized by subtlety, empathy and spontaneity and is associated with intimacy (Lebra, 1994: 117).

As has been shown in interaction:

Emotions are strategic. They play roles in forms of action. And actions occur in situations. So the investigation of an emotion must be widened to include the social contexts. Harré, 1986: 12.

This is an important factor in this study. Describing emotions in strategic and active terms places them as part of the interaction process. Just as thinking is 'still a part of social intercourse' (Mead, 1967: 142) so emotions can be considered in the same theoretical framework. The context of the situation will also be made up of the nursing home setting, with a particular audience. Members of the audience will be part of the interaction process, and their emotions will also be a factor influencing the situation. Staff, visitors and the researcher will all undoubtedly experience emotions within the context of the situation and this will have an impact either directly or indirectly upon the emotions of the central players in the drama, the residents, whose subjective experience I am seeking to understand.

It is the 'subjectivity and the active expressive body' that Freund seeks to engage. He criticises constructionism (such as expressed by Harré) for failing to take account of the biological process of emotions. This is an existential-phenomenological perspective based on the proposition that physical changes accompany cognitive emotions. Through interaction a sense of boundaries develops which places individuals contained inside their bodies as separate from others. In this way we gain awareness of inside and outside and of the emotional boundaries of ourselves and others. Freund sees the inequalities in power of social relationships creating an emotional hierarchy where some people's feelings are prioritised over others (Freund, 1990: 465). In a similar way to Hochschild's management of emotion feelings, this can lead to the subordinate hiding their own emotions which in turn also produces 'dramaturgical stress' (Freund, 1990: 468). So whilst emotions may be experienced within the context of relationships, the nature of the relationships shapes the experience.

Audience engagement and exchange within the emotional system is also consistent with Burkitt's (1997) argument that emotions are always experienced within the context of relationships. Burkitt seeks to get away from the idea of emotions as an expression of an inner feeling and to think of them as 'essentially communicative' and 'occurring *between people* and not something contained inside a single person' (Burkitt, 1997: 40). He

sees emotions as active and arising out of interactions rather than 'based on introspection' (Burkitt, 1997:43).

He concludes:

... the self and emotions are not just a question of positionings within discourses, stories and narratives: instead, emotion is to do with flesh and blood selves, actively bound in power relations and interdependencies, whose embodied expressions and feeling are to do primarily with the relationships between them. This is the matrix in which emotions appear and can properly be understood. Burkitt, 1997: 54-54.

Bringing embodiment into emotions as Freund and Birkitt do, allows acknowledgement and explanation of physiological changes in the body accompanying emotions. When set in context of the social situation of relationships it also allows some significance to self feelings.

The social context is helpful in starting to understand emotions along with the concept that emotions occur and are experienced within the context of relationships. However, these relationships may not always be with others. If we return to Mead's concept that thought is social and an 'inner conversation that goes on' (Mead, 1967: 141), and that we may have relationships with ourselves and with others from the past, present or future, be they real or imagined (Mead, 1967: 143), then this produces a more complete and relevant theoretical stance from which to study people with dementia. This also places the study of emotions within the same theoretical basis as other interactional aspects of relationships in this study.

A sociology of emotions has been shown to consist of many of the elements of everyday life sociologies. As with interactions emotions are used to respond within relationships. Although thought to be the private and inner part of the self, emotions can also be managed, staged and displayed to project the impression that a particular feeling has arisen. Impression management is the emotional labour, and the emotional work, frequently done by women in the interests of others. In this way, it serves the emotional needs of others to the detriment of self feelings.

Different academic disciplines have historically focused upon physiological changes of emotions or upon cognition of emotions. A sociology of emotions can acknowledge bodily changes accompanying culturally shared emotional experience.

Emotional memories are thought to be strong and triggered by contextually similar situations to their original occurrence. It is thought that emotions may, in fact, have a positive effect upon memory for people who have dementia.

When emotional systems are considered in relationships, power and control becomes a factor. Emotions like interactions are used strategically. They are also experienced culturally within the context of relationships, with shared meanings. These emotional relationships should, I believe, also be considered to be occurring with the self, and with others from the past, present, or future. Whether these are with real or imaginary people is of

little relevance. By the use of typifications and common-sense constructs, they are experienced and interpreted, and through this process become the emotional reality.

Conclusion

The theoretical basis for this study is everyday life in the social world, an appropriate basis from which to gain the subjective experience of active social participants. From this I wish to understand the social meaning of that which is taken for granted by my research participants, who have dementia and live in a private nursing home.

Through shared symbols meaning is derived in interactions with others, and in thought with the self. Once the meaning of symbols and gestures are learnt they form the basis of both communication and thinking.

Shared understanding extends beyond gestures and symbols in typifications or what may be typically so. A series of common-sense constructs form the basis of a province of meaning. People with dementia have often been thought to have lost this understanding when they have communication impairments. However, through the perspective of an alternative to the disease model, people who have dementia can be considered on the same terms as those who do not. By examining shared understandings as would be done for other people, taking into account context, background and shared experiences, impairments that may occur are not necessarily attributable to dementia. For instance,

misunderstandings may arise as readily from different biographical backgrounds as from impairments caused by dementia.

When others are involved in our interactions they may be consociates, contemporaries, predecessors or successors. This gives the scope to interact with others living or dead, from the present, past and future. Contextual considerations are important to gain a full understanding of a situation.

In addition to shared meaning through language, the form of conversation is also important and can help our understanding. By using conventions and rituals definition of the situation is aided. We also interact strategically and co-operatively to add to understanding and negotiate our positions in the social world. The dramaturgical model illustrates this well, showing the collusion and corroboration that occurs in social situations.

Significant others and a generalized other are key in our interactions, and help in the development of our sense of self. We play roles to learn about others, embracing some and distancing from others. These also play a part in defining the self. Additionally when deriving a self-image from others it can be a labelled image that we gain. This arises out of differentials in power. Those who are labelled are those who threaten value systems, and are regarded and treated as outsiders.

Once labelled, definition of a person's actions may be reconstructed retrospectively to take account of and justify the label. This is part of the career of deviance that has taken individuals beyond rule-breaking.

Strong influences can project a looking-glass image to the self. Narrative is also a means of self definition. Telling one's own story of the past helps construct the self of then and now. This is a performance where adjustments are made in accordance with reactions from others. Thus, the narrated self is presentational. Like the 'mask of age' it may mask the 'inner self'. It may project feigned conformity and compliance as a form of resistance. Yet it is a means of defining self and presenting an impression of a favourable image to others. It is a way of self categorization.

Boundaries derive from categorization at many levels. They enclose a category, but that which defies categorization lies on the boundaries and is potentially dangerous and also potentially sacred. Boundary crossing also creates ambiguities, as does close proximity or contact with boundaries. These may be controlled and cleansed through ritual and ceremony.

Boundaries are fluid and adjust to changing situations. Three situational domains have been seen to arise from them to account for intimate, ritualistic and anomic situations. Front and backstage, inside and out combine to compensate for these situations.

Times and situations of transition produce particular fear of pollution, often subjected to ritual. Transition is represented by liminality, the actual point of crossing the threshold, the stage 'betwixt and between'. Outside forces control liminality and liminal beings are represented as obedient and submissive. This description corresponds with that of compliant nursing home residents and so provides a useful explanation for the segregation of deviants or transitional people from the main community. It shows how people with dementia have been problematised by not placing the person before the disease. However, within the framework of everyday life sociologies, people with dementia can be seen as active social participants, involved in relationships and interactions with themselves and others.

As with interactions, emotions can be understood within the same theoretical framework of everyday life. They are managed, controlled and displayed, and often emotion work is done in the interests of serving the emotional needs of others. They are experienced in relationships with others and understood in cultural terms. They are a part of active social participation, especially if we also acknowledge that they can occur in a relationship with the self.

Many aspects discussed in this chapter relate directly to social control: labelling, gossiping and conformity are three that are key. They demonstrate how control is exercised by the threat of exclusion from the group. But they also offer the opportunity for individuals to make strategic use of these means to appear to belong or conform, whilst in fact resisting.

These are important issues in relationships and in situations where groups live together as is the case in nursing homes.

These points form the basis of my theoretical framework. By placing people with dementia before the disease process of dementia, it has been shown that an appropriate theoretical framework for this study is one for study of any group of people. This basis is everyday life sociologies which show how people conduct relationships.

The two theoretical chapters outlined so far, in part, guide the methodology of the study. This is the subject of the next chapter, which will complete the theoretical background of the ethnography.

Chapter 4: Gaining the subjective

perspective: Methodological considerations

Theories of everyday life provide clear guiding principles on how to conduct empirical research. The central conceptions of symbolic interactionism describe people acting on the basis of objects in their world, defined and interpreted through interaction. This process of interpretation and assessment allows a construction of social acts in changing situations (Blumer, 1986: 50). Blumer uses these concepts to develop methodology:

... if the scholar wishes to understand the action of people it is necessary for him to see their objects as they see them. Blumer, 1986: 51.

This requires taking the role of others and gaining 'sympathetic introspection' through participant observation. Blumer says we should:

... take social interaction seriously. It is necessary to view the given sphere of life under study as a moving process in which the participants are defining and interpreting each other's acts. Blumer, 1986: 53.

In studying the form of interaction, Blumer says this interpretative aspect is an ongoing process in changing situations and has to be viewed as such, rather than being fixed. His methodological summary is brief and reinforces his resolve that research should:

Respect the nature of the empirical world and organize a methodological stance to reflect that respect. This is what I think symbolic interactionism strives to do. Blumer, 1986: 60.

Symbolic interactionism is the main basis from which my theoretical framework was developed in the last chapter. Blumer's guidelines on methodology also provided a good basis for methodological consideration

in my study. My aim was to consider the natural setting and to gain an understanding of social actions, interactions and interpretative processes for research participants.

As was shown in Chapter 2, dementia research has predominantly been undertaken from the perspectives of carers or health professionals. In recent years this has come in for a certain amount of criticism, from those interested in the people behind the disease and in gaining their views (e.g. Cotrell and Schulz, 1993; Kitwood, 1997). As I wished to consider the people behind dementia and to see them as active social participants, an appropriate methodology, which gains the subjective view of any group, would seem equally appropriate for my study.

Relationships are a part of everyday life and interactions occur by various means and with various intensities throughout the day. Many of these social contacts are so much a part of everyday life that they are taken for granted. Others may be more significant. In order to gain an understanding of them, I wanted to study what was occurring at different times of the day and to discover what opportunities for interactions were presented. It was for this reason that I wanted to study people in the environment in which they lived and to restrict the number of research participants so that a depth of knowledge could be gained.

To provide the subjective view of dementia, my research participants clearly had to have, by some definition, dementia or a dementia related

condition. Appropriate means of contacting people in this situation were through service providers or carers. Whilst I was seeking to gain a depth of information, I wanted to learn more than would be reported to me in interviews, or in intensive and intrusive visits to individual's homes. Home visits were thus eliminated as an option. I considered and visited a number of day-care options, all of which were interesting and all of which left me wondering what happened to people when they went home. This is a potential study for the future. However, the logistics of negotiating access and consent were complex. I was also aware that PhD study presents the perfect opportunity to make choices based on personal preference rather than on those of funding providers. This meant that I could select methods not often financed beyond PhD work, involving lengthy qualitative work, in particular ethnography.

By a process of elimination, I arrived at the conclusion that an appropriate place to conduct my research would be one where people with dementia lived. This would place them in their usual or 'natural' setting, where I could visit, observe and interview without the intensity of overtly focusing upon one person at a time. Having conducted further visits to day hospitals, psychiatric admissions wards, longstay psychiatric hospital wards for the elderly, residential homes and nursing homes, I decided upon a suitable setting and started to negotiate access for research.

Access, Ethics and Informed Consent

The setting I had identified as suitable for the fieldwork was a dementia specific nursing home for thirty-six residents, which was split into three wings each housing twelve people. This, I felt, was a good unit size on which to focus my research.

A director of the nursing home agreed to the research, after consideration of a preliminary research plan that I had submitted (Appendix A). A condition of this access was that I should obtain written informed consent from relatives of each research informant and I had already agreed that I would obtain ethical approval for the study. Supplied with a letter of support from the gatekeeper, I submitted an application to the Ethics of Research Committee of the Health Board for the area in which the nursing home is situated. The application form asked questions relating to clinical research such as 'blood sampling', 'radiation exposure', 'biopsies' and 'anaesthesia'; none of which I intended to use in my study. I was also required to enclose details of my methodology, though there were no sociologists, who might be familiar with such methodology, sitting on the committee. After a delay of about two months, whilst this application was considered and presented to committee, the Health Board Ethics of Research Committee duly granted approval for the research to continue.

The interests of the Ethics of Research Committee highlight a disparity of interests between residents, directors of the nursing home and the researcher. To understand the dynamics of this situation one has to take

the role of the other, for without doing so, it would be easy to judge the procedures involved in gaining ethical approval and access to the research setting as false paternalism.

The position of the Ethics of Research Committee is one of overseer. They are concerned that vulnerable people are not harmed in the research process and as such act as a regulating body. The nursing home to which I was seeking access was a private nursing home. Directors need to ensure that they satisfy the interests of overseers like the Health Board who act as an inspectorate of nursing homes. They also need to satisfy clients, usually the families of residents, and this can have a profound effect on presentation, as will be discussed in Chapter 6. My interest was in behaving responsibly and ethically towards my research subjects, so as not to cause any upset or distress. Additionally, I have to acknowledge that I would be taking information that would be a part of my research project leading to professional qualification. If a hierarchy of power, control and protection exists then residents appear to be those with the least of these. Their apparent vulnerability requires sensitivity at all stages of the research process.

Having been granted ethical approval I mistakenly believed that the next procedure of gaining access to the research setting was to negotiate consent with residents' families. It was with a certain amount of surprise and a great deal of disappointment that I found that this was not the case. The gatekeeper blocked progress for a further five months before I could

proceed. As time passed, my anxiety increased, not knowing if I would gain access, or consent from families, or as I also wished to do from residents. At this stage I had not even seen inside the residents' area of the nursing home.

My anxieties, thankfully, proved to be unfounded. Over nine months after my initial approach and first meeting with senior staff at the setting, which I call Deer View Grange Nursing Home, I was shown around residents' areas of the home and was able to start negotiation of the consent process. I was given a great deal of assistance and co-operation from this stage onwards, with staff from the nursing home forwarding my correspondence to relatives. As a result, I received written consent for nine residents to be involved in the research.

From the outset, I had never expected to gain consent to research all twelve residents in one wing of the nursing home and it had been a matter of concern as to how I would deal with this during fieldwork. What I did was to exclude any information concerning residents who were not a part of the study. Thus, interactions and exchanges that I observed and had with residents who were not a part of the research, were not recorded, and do not form any part of the resulting work.

As already mentioned, studies of the subjective experience of dementia have, to date, been restricted. As I approached the research, I learnt one reason why this is so. Dementia can cause communication and memory

difficulties for people who have it, and this presents challenges to find ethical and sensitive methodologies to conduct the research. The first of these challenges concerns the matter of gaining informed consent to research.

Consent

There is a wealth of literature suggesting that ethically there are three components of valid consent (Berghmans and Ter Meulen, 1995; Helmchen, 1990; Kane, 1998; Marson *et al*, 1994). These are that the person is informed, that they are competent and that they give consent freely, that is they are not coerced. All three aspects of consent, in this definition can be problematic for people with dementia. They require understanding, equal power relations and decision-making capacities. Each of these will be discussed here in relation to the consent process.

For a person with dementia the issue of competency is crucial to the question of informed consent to research. But, as Marson *et al* (1994) point out, incompetence cannot be assumed because a dementia diagnosis has been made. Competency is specific to time, place, situation and one cannot, or should not, talk of competence as a global 'measure'. The reality should not be "Is he/she competent?" but rather "Is he/she competent to do X in Y context?" (Marson *et al*, 1994: 8). Similarly Dubler explains that competence is not only dependent on ability but also upon the

sort of decision to be made (Dubler, 1985: 250). There may be values of long standing which determine the outcome and:

... strong preferences often survive major cognitive deficits and should be given effect, especially if supported by statements of family and friends. Dubler, 1985: 251.

It could be said then that competency presents a dilemma in gaining informed consent from people with dementia. This dilemma has two parts to it: firstly, who decides who is competent or not to give informed consent to research, and secondly, if someone should be deemed incompetent what options may be available for consideration. The question of who decides competence or incompetence is linked to power relations and knowing the person and is by no means unproblematic (Dubler, 1985; Kane, 1998; Marson *et al*, 1994; Roth *et al*, 1977).

If competency is the dilemma in gaining informed consent for research involving people with dementia, solutions need to be sought when someone is deemed incompetent to give consent, or if their competency is in question.

Perhaps the easiest solution is to exclude the person deemed incompetent to give consent from the research process. This is arguably one of the key reasons why dementia research has focused on second-hand accounts from carers rather than on the person as first person informant. Exclusion of this group from the research process can clearly lead to sample bias, and loss of information and understanding of these people.

It had always been my intention to obtain informed consent from all participants in the research. At no stage did the Health Board Ethics of Research Committee, the gatekeepers, or family members question me on this, or show concern that I should obtain residents' consent. I believe it is ethical that this should take place and gave a great deal of consideration as to how it should be done.

There have been suggestions that because of the nature of dementia, that someone may consent to research on one day, and forget who you are on a return visit, and therefore negotiation of consent should be continually re-negotiated. In fact, it is an element of informed consent, that if it is given at one stage it cannot be assumed to be for an unlimited period. For instance the British Sociological Association Statement of Ethical Practice states,

... obtaining of consent to be regarded, not as a once-and-for-all prior event, but as a process, subject to renegotiation over time (1.b.v.).

It became an integral feature of my methodology that consent to participate in the research be continually negotiated with residents and this became an interwoven element of the research.

I did not obtain written consent to research from residents. It was not a condition of access or ethical approval that I should and I felt it served no practical purpose to do so. So whilst no tangible proof exists, my method of informing residents and seeking approval from them satisfied my own sense of ethics. The British Sociological Association Statement of Ethical

Practice does not state that written consent should be sought. Where written proxy consent was sought, this was to satisfy a condition of access:

In some situations access to a research setting is gained via a 'gatekeeper.' In these situations members should adhere to the principle of obtaining informed consent directly from research participants to whom access is required, while at the same time taking account of the gatekeepers' interests.

British Sociological Association, Statement of Ethical Practice, 1,b,vi.

A conversational style of research was used throughout the fieldwork, and this is how I told residents what I was doing, what I would use information for and how it would help me. I would frequently make this part of our interactions and ask if it would be acceptable for me to use information gained. To the best of my knowledge, all nine residents who participated in the research understood what I was doing and agreed to be a part of the research. When consent had not been granted by relatives, I did not record information about or given by these residents and did not seek to involve them in the research process.

Access, ethics and proxy consent are all methodological considerations in the research process, having a bearing on what, where, who and how can be researched. For people with dementia in this study, these decisions were all made without their involvement; their voices were silent. Such is the power of gatekeepers and ethical regulators that this could not be changed. My aim from this stage of the process was to redress the balance, and this had a strong influence upon the style of fieldwork conducted.

Fieldwork

The methodological considerations for this study needed to be appropriate for the setting, take account of the vulnerability of research participants and facilitate hearing their voices. This would ensure that my research aims, to gain the subjective view of dementia and to show research participants as active social participants, would be achieved.

My approach to analysis of data will be set aside until Chapter 5 in Part B of the thesis. But now, I wish to describe my approach to fieldwork and the relevance of ethnography, participant observation and interviews. Starting this, a note on the relationship between theory and fieldwork would be useful.

All stages of the research generated ideas and topics and a certain amount of theory was generated by data. This was consistent with the process of 'emergence' from grounded theory (Glaser, 1992).

In a commentary on one researcher's (Clarke, 1997) use of grounded theory, Strauss and Corbin (1997) highlight an occurrence where instead of theory emerging it is constructed and interpreted by the researcher. It demonstrates how the researcher can facilitate the participants' voice through interpretation, when they may have difficulty speaking for themselves:

... actors' own words and interpretations are necessary, respected, but recast in new and analytic terms. Strauss and Corbin, 1997: 64.

This concept of enabling is also consistent with ethnography and discovering the world of others by establishing relationships which create the opportunity for participation and observation (Agar, 1996: 31). What arises from the data are surprises, or 'rich points' followed by 'repeated fine-combing' to understand what the rich points mean (Agar, 1996: 45). They guide the fieldwork that follows, to discover more details, or lead to new theme areas.

Grounded theory has been criticised for rigidly insisting on research having no preconceived ideas about theory. It has been described as 'abstract and removed from the everyday lives of people' (Layder, 1998: 18).

To say that my data determined my theoretical framework would be misleading and would be denying my own biographical and sociological background. However, there is an element of theory being driven by the data, perhaps better accounted for by 'adaptive theory' which:

... attempts to combine an emphasis on prior theoretical ideas and models which feed into and guide research while at the same time attending to the generation of theory from the ongoing analysis of data. Layder, 1998: 19.

Although I am dealing with my analysis separately, it is a process that started and was ongoing throughout the data collection process and beyond. Adaptive theory allows a more flexible approach than grounded theory, where both 'theory-testing' and 'theory-construction' (Layder, 1998:

15) can coexist, and this aids the development of theory, fieldwork and analysis.

The fact that the methodology was qualitative rather than quantitative is closely related to being sensitive, allowing time and not wishing to follow fixed questioning. As Okely found in her study of Gypsies, their answers could not easily be 'coded' and much of the information asked of questionnaires could be gathered, in greater depth, informally (Okely, 1992: 39). I felt that this would also be the case for my study.

Symbolic interactionism already offered a framework of social exchanges and negotiation in relationships that demonstrate active participation. This 'image of humans' (Meltzer *et al*, 1980: 67) was what I also wished to demonstrate for people with dementia, therefore showing them firstly as people.

Ethnography

Seeking the subjective perspective of dementia, from the people who have it, was my aim from the outset. This was important for the study because I wanted to get at the meaning of having dementia, not from other peoples' interpretation, but from people who have dementia themselves. If this were to present me with enough evidence to learn what this meant to individuals, this study needed also to gain depth of understanding. I wanted to know about everyday life with dementia and about social interaction and relationships. The data required for this depth would be qualitative,

requiring intensive research with limited numbers: this study would be an ethnography.

Ethnography is 'an ambiguous term, representing both a process and a product' (Agar, 1996: 53): the process being the fieldwork and analysis and the product, being, in this case, the thesis. The ambiguity of the term accentuates how interwoven fieldwork, analysis and writing are in the research process. It also shields the diversity of opinion on what ethnography is.

Most of the debate seems to focus upon diversity of disciplines. Anthropologists have tended to 'go and *live* with the people under investigation' whilst sociologists become participant observers of people at specific times (Jackson, 1987: 13). But these differences are also a part of temporal development. Classical studies by Malinowski (1922), Mead (1943) and Whyte (1943), were produced by the method of living with the people under investigation and produced 'objective field reports' (Plummer, 1999: 641). Recent, fly-on-the-wall docu-soaps have displayed a new, and public, ethnography 'where lives are recorded by cameras as they are lived' (Plummer, 1999: 642) and 'ethnographers and subjects exchange not just voices but embodied emotions' (Plummer, 1999: 643).

There is now more opportunity for the voice of the researched to be heard, either above or alongside the researcher's and I believe ethnography facilitates this. What I would propose would be an ethnography lying

somewhere between classical anthropology and public ethnography; a 'participatory methodology', where the voice of the research is heard through the authority of ethnography as Agar suggests (Agar, 1996: 15).

Gaining the subjective perspective is in itself a temporal development of ethnography. As Lyon points out, with the growth of 'applied' ethnography, and the extension of this method into more disciplines, researchers are encouraged to include participants in collaboration:

... to help design effective strategies for collecting their voices and to interpret the results. Lyon, 1999: 623.

I did not employ research participants to engage in research design as others have (for instance, Duckett and Fryer, 1998). But I did learn how to communicate with informants by being with them and taking the lead from what they did and how they communicated. In this way they did help in the design of 'effective strategies for collecting their voices'.

The research plan detailed 'stage I' lasting about four months and consisting of observation of the group, 'stage II' focusing on individuals and lasting for four to five months and 'stage III' consisting of a gradual withdrawal from the group and lasting about a month. It would involve non-intrusive participant observation and interviewing.

The original plan for this was written and submitted firstly to Directors of Deer View Grange Nursing Home and later to the Health Board Ethics of Research Committee. The only amendment made to the plan (Appendix A)

was that written consent for inclusion in the study be obtained from relatives of individuals. This change was made at the request of one of the Directors of Deer View Grange.

Participant observation

Participant observation, like ethnography, has variations 'covering several combinations of participation and observation' (Gans, 1999: 540). But what makes it unique is that:

... it allows researchers to observe what people do, while all the other empirical methods are limited to reporting what people say about what they do.
Gans, 1999: 540.

This is an interesting distinction setting observation apart from other aspects of my fieldwork such as interviewing. As Gans pointed out, the balance of participation and observation varies. This could be seen on a covert-overt continuum with categories of 'complete participant', participant-as-observer', 'observer-as-participant' and 'complete observer' (Burgess, 1984). Or in a similar way 'nonparticipation', 'passive', 'moderate', 'active', and 'complete' (Spradley, 1980). My position, like the method, varied at different stages of the fieldwork, and also often within a visit, though I did not reach the extremes of the continuums.

In the early stages of the fieldwork, my role would have appeared, and by Spradley's definition was, passive. This was a deliberate strategy to encourage active participation by residents in the study. I would enter the lounge of Lavender Wing, where most of the research took place, and sit, if

possible, with vacant seats next to me. This gave me the opportunity to observe and residents the opportunity to get used to me. Most importantly, it allowed initiation of approaches and interactions to originate with residents. I was waiting to be approached by people with dementia and for them to talk when ready. This was one way which I felt would minimise researcher influence and bias, as I was conscious that there were inequalities of power in the research relationship. I did not wish to increase the 'arrogance of research' (Bowes, 1996: 5) but to observe active participation by residents.

In two other senses, even in this passive role, I was an active participant, firstly, because I was doing what the residents did. This mirroring of behaviour facilitated familiarisation with my presence and a separate identity from staff. Detachment from staff, though not always successful, was to enable relationships that residents might establish with me to be made on their terms, rather than on the same basis as relationships with staff members. Mirroring residents' behaviour would be the closest I could get to role play, and was an effective means of assuming a certain amount of 'sympathetic introspection' (Blumer, 1986), a means of empathising with residents. Secondly, participant observation could never be considered as passive: it was a role that I found very demanding. It required, in addition to the observational skills, active memory skills and reflexivity:

There are also unconscious ways in which the fieldworker adapts and more fully participates. You learn through the senses and in the body. Posture and movement synchronise with those around.
Okely, 1992: 45.

These unconscious adjustments became shifting roles as I crossed the boundary between outside and in, passing the 'nurses station' on each approach and departure to Lavender Wing. Though most times I also consciously prepared myself on the walk to Lavender Wing Lounge, the walk was often cut short by a resident meeting me in the corridor, which would then initiate the start of fieldwork.

I had only intended that 'stage I' of the fieldwork would take place during the first few months that I was visiting Deer View Grange. In the event the information I gained on each visit was so central to the ethnography that I continued with this observation throughout the nine months of my visits. One of the reasons for this was directly related to residents in the study. If I were to facilitate the voice of all participants in the research, I needed to use suitable methodologies so as not to exclude those with language impairments. If I were to facilitate voice, I did not want this to exclude some. My aims were not to 'favour a united line to competing voices' (Shakespeare and Watson, 1997: 299) as has been the tendency in the area of disability studies, or to favour only voices agreeing with my own (Gubrium and Holstein, 1999), but to try and find ways for all voices to be heard.

In this way, though I did not consciously realise it at the time, I was taking a lead from Blumer whose 'image of humans dictates his methodology' (Meltzer *et al*, 1980: 67). In seeking active participation from residents, I was also seeking elements of symbolic interactionism by examining how

people negotiate and make sense of everyday life through interactions and relationships.

Interviews (stage II of fieldwork) were not possible with all residents, but valuable information could be acquired by spending time with individuals and interacting in different ways. Eye contact and touch were important in these instances and it was a common characteristic that social skills persisted beyond language.

Interviews

Even though I decided to continue with recording and observing throughout the research, by week twelve of the process I was also ready to progress to interviews. By now my level of involvement with residents had increased and I was engaging in regular conversations most times I visited. I would usually circulate from chair to chair in Lavender Wing and spend time with each participant in the study, greeting them on arrival and making farewells on departure. I had also become an informal helper in the lounge of Lavender Wing, taking tea to residents, collecting cups and perhaps filing a resident's broken finger nail. These were things I had witnessed visitors doing. I did not lift residents, or assist them to the toilets, as I wanted to ensure that I did not encroach on care assistants' territory, or appear to be a care assistant to others.

My informal helper role did help in the initiation of interactions by residents. Most were pleased to get a cup of tea and would like to make exchanges of conversation at this time, either verbally or with a nod and a smile.

Now engaging in the interview stage of fieldwork (stage II), occasionally, I would revert to observer role, if I wanted to review something I had seen on a recent visit. This indulgence was not always permitted me by residents because they seemed to want to greet me and chat. So it was that on some of my visits that I would produce a tape recorder, explain what it was for, ask the resident(s) involved if they would allow me to tape our conversation and proceed in this way.

Interview formats can range between structured which closely follow a schedule, to unstructured or focused, where interviewers follow a list of topics (Fielding, 1993: 136). At the one extreme, unstructured interviews are used:

... when we need very detailed and extensive data ... where the subject matter is sensitive or complicated. Fielding, 1993: 138.

This was clearly the case in this research. My only tool in interviewing was an audio tape recorder. Using neither interview schedule nor guide, which would have focused the interviews, I tried as far as possible to let residents lead the conversation. These interviews were very unstructured, conversational and followed whatever direction residents wished to go in. Sometimes, residents would ask what I wanted to know, or what they should talk about and I would tell them they could talk about anything, 'the

way we usually do'. In this way, the tape was soon forgotten and the conversation would take place.

Within the conversations I had with residents, sometimes taped and other times not, my efforts to minimise influence would often lead to a monologue. These '(V)oces in the field' (Gubrium and Holstein, 1999: 562), were narratives of lives, loves and selves, in the creation of which I was required to play a supporting role. In contrast to the authoritative voice of the ethnographer, who spoke for research participants, narrative allows participants to speak. But, as Gubrium and Holstein point out, ethnography and narrative can combine with careful management of the border between them. We should not privilege one above the other, or select only voices enhancing our own.

The fruitfulness of treating field research as a kind of border work between narrative and ethnography is that it directs us to elaborate ... constitutive nuance while aiming to document social organization. Gubrium and Holstein, 1999: 571.

Narrative and ethnography can complement each other, adding qualitative and authentic data to the interpretations of the ethnography. The skills of the ethnographer are in exercising patience and learning to listen, and in this way to act as a conduit for the resulting rich data.

Taping interviews, and later interpreting the data, was not without problems. The process of producing the tape recorder, explaining what would occur and asking permission of the resident could be awkward and intrusive. I often felt I was missing more valuable observations and that the flow of conversation had been interrupted. Interviewees often had declined

language, speech impairments and spoke with local dialects, which I did not share. There was a strong reluctance to leave the lounge area of Lavender Wing to tape an interview, and we competed with the noise of a hi-fi system, vacuum cleaners, other residents and staff exchanges. These did not seem to hinder interactions for residents as much as they did for me. When I came to transcribe interviews, I realised how much of the data was consumed by these distractions. In face-to-face interactions, the social cues, the looks and context add so much. Without these the richness of data fell short of other conversations I had with research participants.

It often seemed to be the case that key conversations occurred just after the tape had been switched off. I did sometimes wonder if the tape recorder had inhibited interactions. Over a period of two months, I conducted nine taped interviews with four residents and at the end of this period I decided to stop taping interviews.

Fieldwork in perspective

The fieldwork took place from April to December 1999, over a nine-month span and loosely followed the research plan. Nine residents were involved in the study which consisted of around 90 visits totalling over 200 hours of fieldwork. The majority of my visits were made on weekdays during the day, but I also visited at weekends and made a point of visiting at all times during the 24-hour day at least once. As activity in the public areas (this will be discussed more fully in Chapter 5) of Deer View Grange was greater

between the hours of 6 am and 6 pm, this was when the majority of my visits took place.

'Stage 1' consisted of participant observation. This would have been an apparently passive role for those exerting the 'gaze' at me, and was deliberately so. During the first few visits I did not initiate conversations or make deliberate eye contact with people. My aim was for people to get used to my presence and not to feel pressurised by me. In particular, I did not want residents to identify me with staff, and establish a relationship with me on the same basis as any they might already have had with staff. I was not always successful in this. Prior to the commencement of the fieldwork I had held two information sessions for staff and circulated a written account of what I would be doing. None of the care assistants came to my sessions and the only member of staff who did was in a management position. My opportunity to inform care staff was therefore lost. This meant that when I did start visiting to conduct fieldwork I was met by a certain amount of curiosity from care staff.

Curiosity waned as residents and staff alike became used to me just being there. As time went by people seemed to accept that I would be about and questioned me less. I really felt I was getting somewhere when several months into the research one of the Directors stopped on her way out of the lounge and said "I'm really sorry Gillian, I didn't notice you there, you just sort of blend in now."

My level of participation with residents continued to be high until late into the nine-month period. By November, I was feeling a little disappointed about my cessation of taped interviews and was wondering if I was now really collecting any data that was significant for the study. I was not really sure if I had reached 'saturation' of my data (Strauss and Corbin, 1998: 136), or if I should continue visiting to research at all. I may have been experiencing the 'fighter pilot' stress of travelling and adjusting between cultures (Agar, 1996: 102). However, I did enjoy visiting Deer View Grange and the residents involved in my study, so I decided to continue for a while just as a visitor.

Stepping back from the intensity of the study brought new life to my fieldwork. It gave me both renewed enthusiasm and data that I might easily have missed. Concurrently with this metamorphic stage I was able to conduct an interview with the Deputy Matron for general background information and very brief interviews with the care assistant most closely associated with each of the residents in the study. None of these was taped, but as they were conducted away from the research area, I did use a note book during interviews to record responses. It was important to me that these interviews were conducted at a late stage in the research process as I did not want undue influence to intrude into my earlier data collection from the first-hand informants. Access to records containing dates of birth and dates of entry to the Nursing Home were also given to me for descriptive background data.

By December I was ready to move into 'stage III', the final stage of the fieldwork, a period of gradual withdrawal. As Stalker points out:

When ethnographic methods are employed, especially within people's own homes ... (there are) worries about setting up expectations of continuing friendship which might not then be realised.
Stalker, 1998: 10.

This concern was the reason that I had built this period of withdrawal into the research design. It was interesting that this was necessary for me, probably more than for others, so that I could get used to the idea of not seeing residents so regularly.

The high spot of this stage of the research was the Christmas Party, an event for residents, relatives, staff and friends. It was a chance to relax, celebrate and enjoy the occasion; it was almost the last time I visited before the end of the fieldwork.

Recording data

There were a number of skills that I needed to develop to observe, interview and record research data. During fieldwork, I never took pen, pencil or notebook into the residents' areas of Lavender Wing. It would have altered the appearance of my role, and might have seemed intimidating. After each visit I would leave Deer View Grange Nursing Home and stop as soon as I could find somewhere quiet and private to make notes on everything that I had observed. Later that day, or the next morning, I would type up my notes on a word processor. It was a discipline I am glad I maintained because the amount of data to be typed never

became too arduous and it also gave me an opportunity to reflect on events before making my next visit for fieldwork.

The length of my visits was between two and four hours, and this was a period of time that I found I could observe, absorb and retain information until I came to write it all down. My journeys home were a chance to unwind and reflect, but strangely after observing intently in my fieldwork, I often found I would be checking how many passengers passing cars carried and what the occupants were doing and wearing. I had a heightened sense of awareness.

Also, as part of the reflexive process, I kept a research diary. Lee-Treweek (1996: 117) describes how she did this in her research. In a similar vein, it allowed me to make lists and jottings which usually occurred to me early in the morning when research thoughts were at a subconscious level. These proved to be invaluable in identifying emerging themes.

After conducting taped interviews, I again disciplined myself to go over the data as soon as possible while events were still fresh in my mind. I transcribed all tapes verbatim and added notes of actions not captured on tape as I remembered them.

Recording of data, and indeed generation of themes during the fieldwork process, were the start of analysis of data. Whilst this may be a false

division I am dealing with analytical matters separately in the next chapter as they seem best grouped with an introduction to the setting and sample.

Conclusion

My methodology has been considered in relation to the theoretical basis of the study, the research participants and the aim to gain the subjective perspective. The first of these considerations focused on gaining access, ethical approval and consent. When dealing with vulnerable people, such as those living in a nursing home and those who have dementia, aspects of these processes highlight the sensitivity of the issues. One of these, that is particularly relevant when people may have memory impairments, is that consent negotiation should be continual throughout the fieldwork period.

Throughout the research process, there was a certain amount of theme emergence from the data collected. This is consistent with grounded theory. However, I was also clearly working to a theoretical framework based on everyday life sociologies, and like Blumer driven by, rather than creating, an image of humans. This image, for me, is of active social participants. From this viewpoint my methodology is therefore more based on adaptive theory which allows both for theme emergence and pre-conceived notions of theory.

Based on ethnography, my fieldwork consisted of participant observation and interviews carried out over a nine-month period. I chose to do

ethnography, firstly because I thought it might be my only opportunity to use this method. Secondly, as Orona 'kept hearing the background' (1997: 177), a description of her setting determining her method, my setting also spoke to me to undertake an ethnography.

Some of my method was adjusted to take account of the individuality of my research informants. Originally designed with little knowledge of people with dementia, I had not allowed for the subtle ways in which those with language impairments may communicate. Rather than being able to interview these people, the emphasis changed to engaging eye contact, touch and spending more time individually. This, I felt, allowed for multiple voices to be heard, rather than just the ones that could be articulated. Additionally, I found that even with those who could engage in tape recorded interviews, there was a great deal of information not captured on the recordings. This consisted of looks and social cues, but also consisted of my definition of the situation. It highlighted that context cannot necessarily be captured on tape.

My definition of the situation is clearly part of the analytical process of the research, as was the reflexivity resulting from the research diary I kept. A fuller discussion of analysis will be given in Chapter 5, the first of the analytical chapters.

Part B

Part A of the thesis has been involved in setting the theoretical and methodological scene for the analysis of the data in Part B. It is worth at this point summarising this before moving on to analytical matters.

Looking back at how the scene has been set

This ethnography is about people who also have dementia and also live in a nursing home. By asking 'whose dementia is it?' perspectives on dementia are examined which include attitudes, stereotypes and models by which it is characterized. Reflecting on these attitudes, and on lessons from disability studies, helps position my own work. Relationships, personhood and hearing the voices of those who have dementia can therefore directly act as critiques of the dominant medical model of dementia, which, in focusing on disease, ignores individuals who have it. Matters relating to power, control, surveillance and the culture and rule-bound operation of nursing homes demonstrate environmental constraints. How people cope with, or offer resistance to these, shows the level of active participation, and perhaps suggests an alternative way of voicing subjectivity.

The theoretical background of the study is based on everyday life sociology, an appropriate means of studying the subjective aspects of dementia because it is based on how we make sense of the social world. Premised on shared understanding, interactions, emotions, dramaturgy and

categorization, study of these elements can provide a depth of information. It also gives opportunity for the aims of the thesis to be met: the concern with everyday social actors enables and encourages the exploration of social competence and active participation by those involved in the study.

The methodological considerations of the study are not without problems. Research participants are vulnerable and may have impairments as a result of dementia. Rather than making these impairments disabling, it is the challenge of the researcher to find appropriate means to overcome them and allow the subjective voice to be heard. The vulnerability of participants presented challenges in gaining access to the setting, in ethics and in consent to research. Matters of the relationship between researcher and researched required sensitivity, and a certain amount of passivity on the researcher's part to allow more activity from participants. I felt this was only possible by an in-depth study, and ethnography provided this opportunity. Ethnographic interpretation is also an appropriate means of facilitating participants' voices, should impairments prevent this.

Looking forward to the analytical chapters

To write an ethnography requires at a minimum some understanding of the language, concepts, categories, practices, rules, beliefs, and so forth, used by members of the written-about group. Van Maanen, 1988: 13.

This is what I wanted to achieve from sifting through my data, to gain an understanding of the subjectivity of research participants. There are five analytical chapters in Part B of the thesis. Further scene setting takes

place in Chapter 5, which is involved with methodology relating to analysis, together with an introduction to the setting and residents. In Chapter 6, I shall try to capture what it is like to live in a nursing home, discussing the benefits and the constraints of living in this environment and what a typical day can be like. This provides the context for the study.

Three main thematic areas are addressed in chapters 7, 8 and 9, relating to emotions, interaction and boundaries. They link in the way they relate to the subjectivity of the people with dementia informing the research. The first of these is concerned with the inner, intimate and emotional self, engaged in thought and memories which are sometimes shared with others. The emotional self is most frequently involved in backstage performances though it may also be displayed in more public performances. Discussion includes emotions of dementia including awareness of dementia for research participants.

The second substantive analytical theme relates to the interactional self, engaged in ritual exchanges. These may be with significant others, a generalized other or the self. The interactional self is most often involved in frontstage performances, but may share a backstage intimacy, depending on the situation and audience.

The final thematic area is concerned with categorization and boundary definition. This is both of and by research participants. Often announcing to a generalized other, the ritual or intimacy of this self adjusts according to

what or who is being defined. For instance, in defining the boundaries of self, more intimacy is involved than in defining others. Emotions may, however, be involved in the tangible boundaries of the building in which informants live, if a confinement situation is perceived.

These are the three key thematic areas of the thesis, and constitute chapters 7, 8, and 9 respectively, to show active participation of research informants in emotions, interaction and in boundary definition. The scene will first be set in the next chapter on analytical considerations, and in introducing the setting and research informants.

Chapter 5: Analytical beginnings: Introducing the stage and players

Having established aims and objectives and defined the theory informing this research, it is time to start examining the data in some detail. This is the first analytical chapter. In it, I describe how I did the analysis of my collected data, before introducing the setting and research participants.

Analysis

It is worth stating at the outset that analysis is not an exclusive or discrete stage of research. It is argued that this is a feature of qualitative methods (Hammersley and Atkinson, 1997: 205, Okely, 2000: 20, Strauss and Corbin, 1998: 57), but Bryman and Burgess say it is also the case with quantitative data analysis (2000: 218). Perhaps this feature is more pronounced with qualitative data because the depth of information from a single interview is likely to provide more meaningful information than a single questionnaire.

Analysis for me was not an exclusive or discrete stage of research either. It started when I commenced my fieldwork. I observed with an analytical eye. Additionally, by disciplining myself to type up fieldnotes and transcribe interviews as soon as possible after recording data, I was able to reflect analytically. This helped generate ideas of what might be important in this study and what might relate to literature in the general area of research. As

these ideas emerged out of the fieldwork I recorded them in my research diary. They thus became topic areas for further investigation.

At the end of the nine-month fieldwork period all my notes had been word-processed ready for further analysis. They consisted of fieldnotes from participant observation, transcribed interviews, demographic information to give ages and length of stay from nursing home records, notes from an interview with the Deputy Matron, notes from interviews with care assistants and my research diary. All these notes were now imported as files into NUDIST, a software package for analysing qualitative data.

As described in my methodology (Chapter 4), I used an approach incorporating grounded theory in data collection to allow themes to emerge and inform the fieldwork. This theme emergence is part of the analysis. Beyond this, I decided not to engage in the complex coding system of grounded theory (Glaser, 1992; Glaser and Strauss, 1967; Strauss and Corbin, 1998). However, NUDIST is a flexible package developed under the influence of grounded theory and it allows for coding and the importation of additional data at any stage (Richards and Richards, 2000: 149). Initially, I used it as a central point to store my project before any coding was attempted. I then read through all my material to gain a sense of the overall data.

Ritchie and Spencer (2000) note that the act of coding takes data out of context. NUDIST has a spread option to display text surrounding coded

data, which helps with context. Richards and Richards (2000), who were involved with developing NUDIST say this is underused and the context aspect of data is linked more to the researcher's theoretical assumptions than to the limitations of the software. So whilst NUDIST is a superb means of organizing vast amounts of qualitative data, and of making cutting and pasting almost redundant, I learnt quite soon that it must only be considered as a tool and not as a substitute for good analytical procedures. I did have theoretical assumptions based upon what I had learnt and read before the fieldwork started. These guided what I did with the data and how I used NUDIST to deal with it. Thus where data clearly related to theory it was noted as such. For instance, I named emotions and coded data relating to the routine of Deer View Grange. Initially, this was by noting these themes in the margins of my data printouts before coding into NUDIST.

It was in a very specific way that I used NUDIST. Before structuring the data I coded it all to free nodes, basically grouping like data under suitable headings. For each of these I also noted the node name on an index card and used these manually to build a tree structure. This I did by placing them on the floor and shuffling them around until a pattern started to emerge. This exercise was one in which my dog participated, coming to see why I found these cards so interesting. He also shuffled them and thus added an additional dimension to the process, requiring much more thought on my part as to where each card fitted best.

As analysis continued, the data were driving the theme emergence and I was beginning to link and search for appropriate theoretical explanations for my findings. Three key thematic areas emerged in this process; they are the ones discussed in the three chapters relating to emotions, interaction and boundaries.

My original conception was that the self engages with others at varying intensities according to the significance of the relationship. I had a concept of concentric circles (an idea that arose from reading the work of Evans Pritchard (1940)), emanating out from the self to significant others and to a generalized other. This proved to be too constraining and developed from concentric circles to floating amoebas, permeating and crossing boundaries (Okely, 1992; Wallman, 1986). This was much less mechanistic, and more consistent with symbolic interactionism. It allowed for fluid and changing situations that Lebra (1982) described as 'situational domains' of 'intimate', 'ritual' and 'anomic'. In relationships these will often correlate to the categories of self, significant others and generalized other, to construct intimate, shared and generalized relationships.

Also pertinent to the three key thematic areas is Goffman's dramaturgical model (1990). According to the intimacy of the relationship and situation, exchanges may be either backstage or frontstage: shared intimacy or ritually courteous. But, both part of and beyond this, there is also a sphere of classification and boundary definition.

The three thematic areas are strongly linked with all of these theoretical domains; that is, they frequently correspond, but not always. The self may be emotional, and engage in backstage and intimate exchanges, sometimes internally in thoughts and memories. Interaction may be shared with significant others in a presentational format, in frontstage performance. However, as part of this, an intimacy may be shared, with a change to backstage exchange. Finally, generalized classification may lead to boundary definition for, of, with or by, a generalized other. This also is accompanied by fluidity, as classification may not always be on this generalized scale, but may be of significant others, and may also define the boundaries between them and the self, or the boundaries of the self.

My index card shuffling exercise produced a pattern which when grouped into similar topic areas would clearly form into five analytical theme areas, the three discussed above plus two others. These were the setting and residents; nursing home culture; dementia and emotions; interaction; and margins and boundaries.

When I was satisfied that a reasonable structure had started to develop, I used my index cards to build a tree structure in NUDIST and imported it to my existing project. Some codes did not immediately fit the structure so were retained as free nodes for later use if appropriate.

The main analytical theme areas and their associated topics are shown in Appendix D, as they became structured in NUDIST. Having organized the

data in this way, I could now code and retrieve data from all documents according to the coding applied. Thus, if I wanted to analyse data relating to, for instance, resident Jane Gilbert, I could compile a report on node (1.2.1) and all data that I coded to this would be included. I also had a basic idea of how my analytical chapters would be formed.

At the beginning of this section I stated that analysis is not a discrete stage of the research process. With data stored, organized and categorized, analysis continues whilst writing. In fact, many of the topics have been worked through, linked to theory and re-written to fully explore and understand them. I expect this process to continue and perhaps take on new meaning in the future. This has been my approach to analysis, an interpretative approach informed by everyday life sociological theories and set in context by the participants and setting. These are now to be introduced starting with the setting.

The Setting

The setting for this ethnography took place in a dementia-specific private nursing home that I call Deer View Grange. I take my definition of dementia-specific from the gatekeeper to the Nursing Home that 'generally residents do have a medical diagnosis of dementia but not necessarily'. They are all, however, thought to have dementia.

The building was about five years old when I conducted my fieldwork, having been built specifically as a nursing home for people with dementia. It was pleasant to enter, well maintained, carpeted throughout; and it seemed that attempts had been made to make it appear more homely than clinical. This involved flowered wallpaper, pictures on the walls and occasional tables and chairs placed in the wide corridors. In summer, planted tubs and hanging baskets surround the entrance to the building, adding both colour and perfume.

Deer View Grange Nursing Home is a modern building, part of a nursing home complex, set in private grounds in the Central Belt of Scotland. It consists of three wings, housing twelve residents on each. Each wing has a lounge, dining area, toilets and bathrooms. Residents' rooms are arranged in close proximity to these. My research was based on Lavender Wing. On this wing each resident has his or her own bedroom with en suite facilities. Plans of Lavender Wing are included in the appendices (B and C).

The entrance to Lavender Wing is shared with other wings in the building and is via two sets of double doors to a reception area. During the day, the reception area is staffed: outside of these times the external doors are locked to outsiders coming in and alarmed to insiders going out.

Inside, the reception area also has flowers. There are cushioned seats for waiting visitors and the receptionist has a work station and telephone

system. On the wall hangs a resident's charter, one which is repeated in the brochures which are available in reception and which are designed to sell the nursing home to prospective residents and their families.

After passing by reception through a third set of double doors, visitors must pass by the Nurse's Station before turning towards the appropriate wing. To approach Lavender Wing, you must first go past administrative offices before reaching the bedrooms and bathrooms of the wing. These line the route to the residents' lounge and dining area.

The general decor of Deer View Grange is of boldly designed wallpaper and dark coloured carpets. Each wing has its own colour scheme, which is designed to help people find their way about. Pictures hang along the corridors, though they are somewhat lost against the heavily patterned wallpapers. Small coffee tables with chairs, are positioned where space permits, there being two such tables on the corridors of Lavender Wing. There are also chairs positioned outside the administrative offices and, on the day the hairdresser calls, chairs are put outside the room positioned between the Nurse's Station and the administrative offices which serves as a hairdressing salon.

Appendix B shows a general layout of Lavender Wing which is both self contained and accessible from other wings. Single bedrooms are situated along the corridor that leads to the public areas of the lounge and dining room where most fieldwork took place. More details of these public rooms

can be seen in Appendix C, which shows a typical seating plan of the Wing's lounge and dining area. I used a blank plan similar to this one to record where research participants had been during my visit. This was both useful to help my recall whilst writing up fieldnotes and to examine if people always sat in the same seats or not. Mobility was a matter of relevance to this, as those needing assistance from care staff were often placed in seats rather than given a choice.

Lavender Wing consists of twelve bedrooms and several large public bathrooms. At the lounge there is a toilet (through double doors) on either side of the entrance. The lounge of Lavender Wing is entered via glass doors. Inside there is seating for twelve people, a combination of three two-seater sofas and six single chairs, all of them being high-backed. There is also a selection of three occasional tables. Diagonally opposite to the entrance is a hi-fi unit for playing music. There is no television in this room, there being one in a separate room for residents to visit. Windows line one wall and large patio doors another.

To the left of the lounge from the entrance, is an archway to the dining area. Within this, there are three tables, each with four dining chairs and at one end of the room a sideboard unit holding cutlery and crockery, and a heated trolley unit to keep food warm. There are windows with an open outlook, on two sides of the dining area. There are no kitchen facilities near to the dining area and the only running water is in the toilet next to the entrance to the lounge. All food and drinks are brought on large trolleys

from a kitchen in another building. Used crockery and cutlery are taken away on these trolleys and returned washed later.

The seating in the lounge is not fixed and was moved around frequently. The only time I saw the arrangement in the dining area change was towards the end of my fieldwork, when the tables were pushed back to make more room for the Christmas Party.

The lounge and dining room form the basis of the public rooms in Lavender Wing. In good weather this is extended outside on to the patio via the patio doors in the lounge. Most of my fieldwork took place in these public areas with some extending into the corridor as residents moved about.

To respect the privacy of residents I had agreed that I would not enter the individual rooms of residents unless invited by them to do so. There were only two residents who did this. Both visits were very brief with little opportunity for observation. Both of the rooms were small, neat, clean and tidy, with little space for private possessions. What there were consisted of photographs in one of the rooms, and a television and crucifix over the bed in the other. Apart from this my observations are confined to the public rooms as defined above.

Research Participants

Of the twelve residents on Lavender Wing, nine were participants in my study, eight women and one man. This gender imbalance was consistent with one that existed within Deer View Grange and so could be considered representative. Initially, it was a matter of some concern to me that I would be present and observing and indeed interacting with residents who were not a part of the study. However, in practice, this was not a problem. When observations and interactions involved the three residents whose families had not consented to research participation these were excluded from my notes, as was the case with residents visiting from other wings of Deer View Grange.

I should now briefly like to introduce the residents, who were selected to participate in the study purely on the basis of living on Lavender Wing of Deer View Grange Nursing Home. This was the wing suggested to me by the gatekeeper to the setting, based on her own thoughts about suitability for inclusion. On this I really had no option but to trust her judgement, as I had not met the residents and knew nothing about them. She told me that families of residents on this wing were, in her opinion, most likely to consent to the research. By definition those living in Deer View Grange all have dementia or a dementia-related condition. I did not access medical records or seek further information concerning their dementia but merely accepted each person at face value and as an individual.

I shall introduce research participants in the alphabetical order of the first names I have given them, as first names were the ones most frequently used to address them. What I want to give is a general impression of each individual, a portrait of their character. The information I shall include will be the resident's age, marital status, details of family who visit, how long they have lived in the Grange and something typical about them. When I know it, I include their previous occupation as the stating of it was important either to them or to care assistants. When it was care assistants who told me of this I state the fact: in all other instances residents reported their occupations to me themselves. Because there is a direct impact upon the individual's social potential, in language or mobility, I have also described people's impairments.

Alice Taylor

Alice Taylor an 84-year-old widow, had lived in Deer View Grange for nearly two years when I first met her. She came from a town about five miles from the Grange and had good local knowledge of the area. She was physically fit, although she did have several falls during the nine-month period of my fieldwork. She loved to get up early in the morning and was usually one of the last to go to bed at night. Her regular visitors were her brother and her daughter who each tried to see her once a week. Alice had a repertoire of well-rehearsed narratives that she told and often sought verification for these from others. She seemed very concerned that she

should get them 'right'. I had many conversational interviews with Alice, three of which were tape-recorded and transcribed verbatim.

Betty MacRobert

The youngest participant in my study was 61-year-old Betty MacRobert, who had lived in Deer View Grange for 15 months. Her husband also lived in residential care and usually visited once or twice a week, staying for a few hours on each visit. She also had less regular visits from her sister and brother-in-law and they often took her out for the day. Betty was physically impaired and needed assistance with walking, she also had shaky hands presenting her with problems in such tasks as drinking a cup of tea. For this, she was always apologising, and I noticed she often declined tea rather than drink it through the straw that she was offered. Communicating little with other residents, Betty often complained to care staff of being tired. If she asked for someone to take her to bed in the day, she was always refused. I played her at draughts several times and despite trying, never won.

Dorothy McIntosh

The longest residing research participant from Lavender Wing was Dorothy McIntosh, a 93-year-old widow, who had lived there for over two years (27 months). Small, petite and smart, care assistants often commented on how beautiful her clothes were and this seemed to earn her a lot of respect from them. Having difficulty with both walking and hand control she needed

assistance with mobility and holding a cup or cutlery. Dorothy's language was also severely restricted, but she was very capable of expressing preferences and appeared to understand more language than she could articulate. I gained much more understanding of Dorothy after some conversations with her visiting niece and was influenced by the high regard, affection and great respect with which her niece regarded her aunt. Through this, I also started to see Dorothy's sense of humour and was able to help encourage this in interactions with her.

Isobel MacDonald

A sprightly 91-year-old widow, Isobel MacDonald, had lived in Deer View Grange for nearly two years. She has never had children herself and her only visitor, her niece was only able to visit occasionally. Isobel is an extremely outgoing and sociable lady who was able to chatter for far longer than the duration of a 90-minute cassette tape. She clearly disliked being alone and was able at times to present very clear accounts of her past life and relationships. Her stories frequently showed that she believed she was in transit on a journey, a belief sometimes expressed by others in the study, though less frequently. Whilst it is tempting to interpret this belief as metaphor for the journey of dementia into a new stage of life, it is probably more related to the travelling she had experienced earlier in life when she was in the armed forces.

Jane Gilbert

A tall elegant lady, Jane Gilbert was a 79-year-old widow at the time of the study and had lived in Deer View Grange for two years. I was told by care staff, that when she moved into the nursing home she was very articulate and had been a beautician. At this time she had, they reported, taken great pleasure and time with her appearance. Since that time this had changed considerably and she now needed assistance in walking. She was quite able to feed herself but would often throw food or beakers of liquid so was always placed at a table alone for meals. At times, Jane loved company, but sometimes she seemed self-absorbed and not needing others. Often chattering apparently incoherently, Jane would sometimes make surprising and profound statements, reflecting how much more aware of her surroundings she was than she appeared.

Jimmy McLean

Jimmy McLean, the only male in the study, was 76 years old and had lived in Deer View Grange for just over two years when my fieldwork began. He told me he had worked as a coal miner and labourer all of his life. His build was slight and his wit sharp. Much of his time was spent in his bedroom away from 'the women', coming to the public areas of Lavender Wing to smoke and for meals. Jimmy was a local man and had daily visits from his family. His sister, when I met her, was very concerned that he might swear at me and just tell me that he wanted to leave the Grange. He frequently did both of these things. When we had conversations there was always a

lot of joking and joviality. He was always puzzled why someone of my advanced years should still be a student and frequently quizzed me on what I was doing.

Myra Bains

Always smiling, often appearing self-absorbed, I was told by care staff, that Myra Bains, had been a nursing sister. Now, 93-years-old she had lived in Deer View Grange for over two years. Her levels of verbal communication were extremely restricted and she needed assistance with walking. With little family left and her son living at some distance, Myra only had occasional visitors. Whilst communicating with her was difficult, it often paid dividends in surprising ways and could be extremely rewarding in the obvious pleasure it gave her. This view was echoed by care assistants, who said when they had the time to spend with Myra, it could be such a pleasurable experience because of her evident enjoyment.

Rebecca Jackson

At the start of my fieldwork Rebecca Jackson, a 79-year-old widow with a large family who visited regularly, had lived in Deer View Grange for less than a year. Staff often said she had not settled in Deer View Grange. Rebecca was a local lady, known to some of the care staff, and had regular visits from family members. She often spent her day pacing the corridor until she was exhausted. She was frequently restless at night and it was said of her that she often 'turned night into day'. Mrs Jackson (she alone

was addressed by title), always wanted to be busy during her waking hours. She habitually seemed to be searching for familiarity and appeared to experience a great deal of frustration if she could not find a word with which to express herself. It was not unknown for her to shout out and swear at others and to have a very clear sense of when she believed an injustice was being done.

Susan Stirling

Susan Stirling, a 71-year-old who had never married, had lived in Deer View Grange for less than two years. Her sister gave proxy consent for her to be involved in the research (expressing the reservation that she was withdrawn at times), though I was not aware that she received visitors. At the start of my research in April 1999 she was one of the most physically able residents on Lavender Wing and enjoyed smoking and the company of care staff. Whilst her physical condition remained good I witnessed a change in Susan during the nine months I visited. Susan and I never really struck up a very good rapport. She was evidently fond of some care assistants and able to communicate well with them. I sometimes felt that she had agreed to talk to me as part of the research, more because she felt that she should than that she wanted to. For this reason, as was the case with all research participants, if Susan did not appear happy talking to me at any time I left her alone, restricting conversations to when they were initiated by her. This did happen sometimes and was all the more rewarding because she did talk to me only when she wanted to.

Conventions used in writing

Pseudonyms are used for my research setting and participants to protect anonymity. The majority of the quotations that I have used are from my fieldnotes, with additional quotes from interviews and diary notes. I have therefore only indicated when it comes from these two latter sources. As these are from notes, I have used a coded abbreviation system. Where I abbreviate reference to research participants this is with their initials. For instance:

The only residents in the lounge on this occasion were AT, RJ and SS. Abbreviated reference to anyone else other than residents involved in the research is enclosed in brackets. Staff are numbered and prefixed by a status designation: CA for care assistants, SN for staff nurses. For instance:

She wanted to go to the toilet and went and told (CA5) 'I want a piddle'.

As I was going up the corridor (SN1) called after me.

Visitors are also numbered and prefixed by V followed by the initials of the person they are visiting:

The lounge was very busy because (VBM1), (VAT1), (VRJ1) and (VRJ2) were all visiting at the same time.

If there should be mention of any residents not involved in the study, they have been given a pseudonym, which is also placed in brackets:

There were no available seats in the lounge of Lavender Wing because residents from other wings were visiting. SS was very put out by this, as was (Sally) and the two of them left together.

Any other people feature only occasionally and so are described more fully rather than coded.

Where verbatim transcriptions of interviews have been quoted, they may sometimes present challenges to the reader. Many were spoken in the Scottish vernacular and I have included explanations where meaning may not be immediately obvious without knowledge of it. There were also many occurrences of repeated words, part words and utterances. The meaning of these may not be apparent. However, they have been included because they indicate when there was struggle to search for a word or when someone was excited or upset. I am also aware that my interpretation of meaning may not have been accurate and inclusion of the original voices gives further opportunity for the reader to gain understanding.

Conclusion

This, the first of the analytical chapters, has been a description of my approach to analysis. The research setting and nine research informants have been introduced: giving a flavour of the ethnography to follow. I have explained the conventions used in writing, to guide the reader further.

It has become apparent that analysis is not a separate or discrete stage of research, but starts and continues throughout fieldwork and writing. By

linking initial conceptions with data and theory, analysis develops to become an interpretation of the social world.

In this study NUDIST was used as an analytical tool to organize and structure the data. This process also gave structure to the analytical chapters of the thesis as similar themes were grouped and linked to theory.

Now, having described how analysis has been done, Chapter 6 will provide an insight into the culture of Deer View Grange, where my nine research participants live in everyday life.

Chapter 6: Social benefits and constraints of living in a nursing home

With the research setting and participants introduced, this chapter is concerned with how the environment may provide or constrain opportunities for relationships for residents.

As has been seen in the literature on nursing homes, there is a particular culture associated with them. This culture developed from the medical model, which sees residents as passive recipients of care and is concerned with routine and efficiency. The medical model makes residents problematic and reduces them to objects in need of surveillance. In the interests of maintaining routine and control a regime is followed whereby residents are exposed and infantilized. Justification for the constant gaze of surveillance is that it is for residents' own health and good and reduces risk. However, in its imposition, residents are denied their privacy and are required to be in public rooms where they can be seen. Control of a group in this way makes more efficient use of staffing. The establishment also operates more smoothly if residents are compliant and passive, following rules, offering minimum resistance and making the least work for staff.

This chapter is concerned with examining the impact that the environment could have on interactions: about how the nursing home may facilitate or constrain the opportunities for relationships. Firstly, to get a flavour of what

it may be like to live in a nursing home I shall describe what a typical day would consist of: this will be a description of the routines of a day in Deer View Grange. It is a description of nursing home routine. Following this, I shall discuss the benefits of living in a nursing home, of opportunities for relationships and then the constraints that may apply.

A day in Deer View Grange; a description of nursing home routine

My visits to Deer View Grange lasted between two and four hours at a time. Visitors usually stayed for shorter periods. Staff were on duty for up to twelve hours and residents were generally there for 24 hours a day. During the course of the research period, my visits were timed to cover all the hours of the day. From this I shall construct what may be considered to be a typical 24-hour period.

Between midnight and the early hours of the morning, apart from strange sounds coming from the laundry, which is busy throughout the night, it is generally quiet in Deer View Grange. It is a time when residents sleep in their rooms. For each wing, a care assistant is positioned in the corridor outside residents' bedrooms, ready to intervene if anyone needs assistance. Mobile residents have sensor pads beside their beds, which alert care assistants by means of an alarm if they should get out of bed. From time to time, the care assistant will look into each room to check that residents are sleeping.

By 3am some residents are starting to stir. This is often just to visit the toilet, which they each have adjoining their bedrooms, after which they will return to bed and sleep. Rebecca Jackson is often restless during the night. She will sometimes wander the corridor but just as often will sit in the chair in her bedroom. These stirrings continue, amounting to activity by no more than four residents, whilst others sleep through.

At 5.10am Susan Stirling is up and dressed, without washing, before the care assistant has realised she is awake. Whilst the care assistant gently persuades Susan that she needs to wash, Alice Taylor awakens and starts demanding attention. Alice is upset: she has overslept, she likes to be first up and now needs assistance because of her agitation. Twenty minutes later Isobel MacDonald is up and dressed by the staff nurse who is helping out. Before the night care assistant goes off duty at 8am she must have eight of the twelve residents on Lavender Wing up, dressed and in the lounge.

By 7.30am care assistants have arrived to do the day shift. Two care assistants work on each wing of Deer View Grange during the day, going off duty at 8.30pm half an hour after the night-shift care assistant has started her duty.

It is 8am and there are eight residents sitting in the lounge of Lavender wing, mainly dozing. Some have been here for nearly three hours. No

refreshments have been offered (and will not be until 9am when breakfast is served). Breakfast arrives from the kitchens, on a trolley, at 9am. All residents are up, dressed, and have been moved to the dining room, unless someone has had a restless night and is being allowed to sleep in. The meal consists of sandwiches, cereal, porridge, juice, toast and tea. Choices are offered, but generally are issued on the basis of what residents are known to prefer.

On Lavender Wing, little assistance is needed in eating, and breakfast, far from being a long and leisurely meal, is over in half an hour. Thus begins the procession from the dining room to the adjoining lounge. In the meantime, a member of the nursing staff has arrived with the drugs trolley and proceeds to issue medicine to residents in the lounge and dining room, according to where they are at the time.

Movement of residents from the dining room is slow, delayed also by visits to the toilet, often with assistance from care staff. People who smoke are waiting for a cigarette and start to get restless and impatient but are told they must wait until all residents have moved from the dining room to the lounge.

Alice Taylor has now been up for over four hours. She is physically able to walk without assistance and has arrived in the lounge before anyone else and, taking up her regular seat opposite the clock on the wall, she now

waits. For her, time is an issue: she often talks of how slowly it passes, of boredom and of waiting.

Eventually, everyone has moved from the dining room to the lounge after breakfast and a care assistant goes to collect cigarettes and a lighter to distribute to those who smoke. The windows are opened and Betty MacRobert, Susan Stirling and Jimmy McLean are each issued with an ashtray. Jimmy keeps his own cigarettes and is already sitting with one, waiting to be given a light. Betty and Susan are each given a cigarette and a light.

With this smoking ritual also completed many residents now fall asleep in the lounge. Jimmy leaves and goes away to his own room where he will read his newspaper, watch the television and probably also fall asleep. He does not like staying in the lounge with the women because he says nobody talks to him.

Rebecca Jackson, Alice Taylor, Isobel MacDonald and Susan Stirling all have good mobility and may get up and have a walk along the corridor and sometimes visit the other wings of Deer View Grange. Residents from other wings also visit Lavender Wing. With seating for the twelve residents in the lounge it can be difficult sometimes to get a seat.

The morning drifts by, the radio usually plays, more often Radio Two than anything else. Some residents doze and others come in and out. On

Tuesdays a hairdresser visits and the ladies are taken along one by one to have their hair done.

The next event is around 11am when a trolley arrives with tea and biscuits. A part-filled cup of milky tea with a biscuit in the saucer is handed to each resident in the lounge and one is taken along to Jimmy in his room. Some residents are woken to take their tea, others are allowed to sleep. If residents are visiting from other wings they are given a cup of tea.

Tea is over quickly and is followed by the smoking ritual. Usually, Betty MacRobert will have asked for a cigarette before this and been told firmly that she must wait. It sometimes seems that if she asks she is made to wait longer.

Between morning tea and lunch little seems to happen. Residents are assisted to the toilet if they require it, or if care assistants believe it is time for them to go. The radio drones on.

I remember sitting in the lounge of Lavender Wing at this time one day feeling a little unwell with a headache. There was no privacy. The radio was neither loud enough to hear nor quiet enough to block out, care assistants shouted across the room to each other, the telephone rang out at full volume and this all added to my feeling of being unwell. I was bored, I did not want to be there and I felt oppressed by the environment. I got up and left. This is not an option open to residents. Those who are mobile

can leave the lounge: they cannot leave the building. Those without mobility cannot leave their seats.

Towards 1pm there is another flurry of activity surrounding the arrival of lunch. All twelve residents of Lavender Wing have been seated in the dining room before the arrival of the trolley. Each person is always placed in the same seat. The food looks and smells good and there is always a choice for residents. Care assistants sensitively say 'Would you like one that looks like this or one that looks like this?' Juice is served with the meal. The drugs trolley comes round towards the end of lunch.

All residents are once again returned to the lounge after lunch and cigarettes are allowed once everyone is settled. The afternoon is a time when visitors often come to see residents in Lavender Wing. For instance, if it is Tuesday, then Alice Taylor's brother will visit, always bringing flowers with him. Betty MacRobert's husband may also be visiting, though he usually comes for the day and has his lunch on Lavender Wing. Rebecca Jackson will often have visitors in the afternoon and early evening. Jimmy McLean's sister usually visits just before lunch time and on Thursday evening a brother will often call to take Jimmy out for a drink at the local pub.

Afternoons may vary, and if several residents have visitors at the same time, can be lively. The tea trolley arrives at around 3pm and residents are given a cup of tea and a biscuit. Guests are also usually offered tea.

Following this, cigarettes are issued to residents who smoke along with an ashtray and light. The windows are opened and the cigarettes are smoked.

There is now little time left before 'supper time', as care-assistants referred to it, which is often as early as 4.30pm. Prior to this, residents are taken to the toilet and moved to the dining room. Supper is served and eaten, the drugs trolley comes round and residents are again moved to the lounge, where cigarettes are issued to smokers in the same way as on earlier occasions in the day.

At 5.30pm the first resident from Lavender Wing is taken to bed. By 6pm there are already four residents in bed. At 6.40pm the last tea trolley of the day is brought down for residents who are still up. There are just five on Lavender Wing, with six in bed, and one resident being showered and prepared for bed. From this time the music in the lounge usually stops and it becomes quiet. Care assistants, being busy putting residents to bed, make only occasional appearances in the lounge and this seems to be a little unsettling for some residents.

There may only be one or two residents still up at 8.30pm when the night care assistant for Lavender Wing comes on duty. There seems to be no hurry in putting these more able residents to bed as they need little assistance. Most residents are already sleeping in their private rooms, so this is a good time for the public rooms, the lounge and dining room, to be cleaned.

By 10pm the lounge and dining room, the centre of all activity during the day, has curtains and blinds drawn, the lights turned out and is shut up for the night. The care assistant on night duty now takes up position, in a chair, in the corridor outside residents' rooms. She remains here all night, responding to noises and alarms, only leaving to take a break when relieved by the nursing officer.

Like the early hours of the morning, this time until midnight is quiet, with little movement from residents. Rebecca Jackson may waken and be offered a cup of tea, made in the staff room and taken in her bedroom. This will probably be all that happens. The new day starts just after midnight.

This may be a rather monotonous account of what happens during 24 hours in Deer View Grange. If the account is monotonous, so is the routine. It is one governed by meals and trolleys. Jimmy McLean and Alice Taylor reflect this monotony in comments:

What can you do in here? Nothing. [Jimmy McLean].

Alice never thought she would end up like this:

All your day is waiting, waiting for this, then waiting for the next thing, always waiting. [Alice Taylor].

There are a few aspects of the day's routine that I should like to comment more on. Firstly, the times that residents start to get up in the morning and go to bed at the end of their day are very early. Those people rising soon

after 5 am still have to wait until about 9 am for any refreshments at all. Examining the time that people get up in the morning, many do rise early by choice, but this is not surprising when you examine the time that they go to bed. A care assistant commented that Rebecca Jackson often 'turned night into day', suggesting that this unusual behaviour was characteristic of someone with dementia, yet residents' sleep patterns had clearly been established to accommodate the routine of the establishment.

With regard to how early residents were starting to go to bed (5.30 pm), I was told by care staff that many residents wanted to go to bed at this time. Certainly Betty MacRobert frequently asks to go to bed during the day. I asked her one day why she was always tired. She was uncertain, so I asked if she slept at night. She told me that when she went to bed her mind 'raced' and she could not sleep. As Willcocks *et al* (1998) found, there is little opportunity for unobserved privacy within nursing homes. Betty MacRobert got uncomfortable if I pursued the questioning further, but I felt that her desire to go to bed was linked to a desire for privacy.

Apart from Betty, those who were put to bed earliest were those who appeared least able and with more lost language. It is possible to speculate that these residents offered the least resistance, or that they did need to sleep for long hours. However, if they had not been got out of bed so early in the morning this early bedtime might not have been necessary. Just as Lyman (1993), and Hockey and James (1993) describe occurring within nursing homes, this infantilizes residents; by giving them a bedtime

more frequently associated with children, they become thought of as children. I can only conclude from this that bedtime, like getting-up time, was planned for the convenience of staff. Those needing most assistance were therefore put to bed while there were still two care assistants on duty instead of the one who worked alone at night. After the long wait for breakfast in the morning, the meal was over quickly; again this seemed to be to accommodate the convenience of staff, who then had to continue with further duties.

Smoking was an issue that struck me as typifying much of what the culture of nursing homes is concerned with. It is one concerned with rules. This is a topic I will discuss later in this chapter when I talk about power and control and also in Chapter 9 where I talk about rules and resistance. It is a topic concerned with restricting choice for smokers and non-smokers, it is also a matter where the power to control is open to abuse.

In order to assess how this environment may impact upon opportunities for relationships and how it may promote or impede interactions some benefits and constraints of living in a nursing home will be considered.

Benefits of living in a nursing home

If Alice spends her day waiting she does not have to do so on her own. This must be one of the biggest benefits of living in a nursing home: to have company and contact with other people. As Isobel McDonald said to

me one day 'They come here to tangle, you know'. All of the residents in this study had lived alone prior to moving into Deer View Grange and all were considered by somebody to be finding it difficult to cope independently. Isobel's profound statement about mixing socially is more pertinent when one considers the unseen plaques and tangles in the brains of people with Alzheimer's disease as described in organic accounts of dementia (such as Jacques and Jackson, 2000).

The standard of care provided in Deer View Grange was heralded by nursing officers at other establishments in the locality as being the best around. Residents appear well fed and looked after. The building is modern and light. One family member commented that it was pleasant to visit and that stress in her relationship with her mother had been eased by her mother's move into care. Instead of the chore of hard work to help her mother she could relax with her and enjoy her company, reassured that she was well cared for in what she considered to be a safe environment.

As Goffman (1991) has explained in his account of mental patients, there may however, be a disparity of view on this between that of family and that of the resident. In the career of the mental patient, the effect of labelling, like this daughter's account of the move into residential care, can be a relief for the family. For the labelled resident placed in care there may be feelings of 'collusion' in the process and 'abandonment, disloyalty and embitterment' (Goffman, 1991: 125). Older people with children have been seen to seek most social support from daughters (Phillipson *et al*, 2001).

When the daughter is the person who has placed the resident in care, this feeling of abandonment may be exacerbated.

Whilst I was not able to discover what the mother of this daughter felt about entering care, I did learn of many other residents' feelings of abandonment. Many mobile residents also frequently had an impetus that I called 'Got to get out', a concept discussed more fully in Chapter 9.

However, for families at least, there seemed to be a clear benefit due to the person with dementia being cared for in Deer View Grange. This benefit amounted to 'instrumental support' (Phillipson *et al*, 2001:119) being provided by the Grange. Part of this meant that in addition to the pleasant surroundings and company of other people in similar circumstances, there is a team of nursing staff who can detect and take early remedial action if illness should occur. They can treat minor conditions and call in a doctor should that be necessary.

Residents on Lavender Wing in Deer View Grange also have activities, events and outings organized for them. Never being privy to them, my knowledge of these is restricted to reports by staff and to preparation before events. These activities do appear limited and often dependent upon the enthusiasm and resourcefulness of individual care assistants on duty. They are almost always group activities rather than doing favourite things with individuals, though some care assistants were more skilled in giving this choice than others. For instance:

When (CA4) was helping residents through to the lounge after breakfast she was asking them where they wanted to sit, at least I heard her ask Isobel MacDonald. I also heard (CA21) ask Rebecca Jackson where she wanted to sit. Both chose the first available seat.

Constraints of living in a nursing home

It is difficult to provide choice in individual activities when so much emphasis is put on all residents behaving and participating as a group, as is the case in the lounge of Lavender Wing. The 'group' is convenient for surveillance, and makes it easy to identify those not conforming to this 'compliance' (Goffman, 1991: 18). To want privacy or to wish to be away from the group was not easily accommodated:

Rebecca Jackson wandered the corridor for a good bit of my visit and I heard later from (CA7) that she had tried to lock herself in her room. 'She then just sat in her room and wouldn't come out'. (SN2) said she wasn't upset at all, but (CA7) and (SN2) obviously thought this was odd behaviour.

Rebecca was carving out some privacy by crossing the 'boundaries between public and private places' (Gubrium, 1997: 33). By choosing to be in her designated private room, she was not easily controlled as part of the group. Within this surveillance culture, her behaviour was considered as strange.

Possessions

An indicator of choice and a key means of developing and maintaining personal identity is the possessions people have. They project an image to outsiders and perhaps more importantly they serve as reminders of a lifetime of memories and experiences to their owners. Personal possessions although encouraged in Deer View Grange are restricted to

private bedrooms. Thus, within the area where most of the waking hours are spent, residents have little to identify them or remind them of their identity.

Efforts at personalisation are made by care assistants by giving a choice in what residents wear in the morning. This concern for residents' autonomy competes with pressures on care assistants' time. Perhaps the real concern was revealed one day when I commented how nice Betty MacRobert looked. 'Yes' said the care assistant, and she continued to explain that she had mistakenly thought it was the day Betty's husband was to visit and had put her best clothes on by mistake:

Presenting well-ordered bodies seemed to symbolize the job properly done.
Lee-Treweek, 1998: 231.

Presentation is an important element of this surveillance culture. It can also be completely out of the control of residents.

Some residents were able and did make efforts to have and guard personal possessions in public areas. Two ladies, Alice Taylor and Susan Stirling, often had handbags with them which they were reluctant to let go of. Other ladies (Isobel MacDonald and Rebecca Jackson) also spoke of not knowing where their bags were, though I never saw bags in their possession. I even saw Susan clutching her handbag one evening in the lounge when she had already had a shower and was in her dressing gown ready for bed. Concern for the safety of bags was expressed when I had my own bag with me, containing my tape recorder:

‘Just leave them there? I wouldnae lift them, I wouldnae leave them here’.
[Interview, Isobel MacDonald].

Alice Taylor, like many residents, was possessive of ‘her’ area of the lounge. She demonstrated a very strong determinism that ‘her seat’ should not be taken by anyone else, or that if anyone were to read the newspaper it would be upon her offering it to them. In this way, she constructed both ‘defensible space’ (Willcocks *et al*, 1998: 82) and defensible possessions. After she had looked at the newspaper herself, Alice usually lifted the cushion of the seat on which she was sitting and slipped the newspaper underneath, then sat back on the seat. On several occasions I heard her call others ‘besom’ or ‘bitch’ because they had infringed her self-made rules regarding possessions. On another occasion when a resident did ‘lift’ Alice’s handbag, an argument broke out between the ladies in which the other resident hit Alice with the handbag. Although her usual derogatory comments were muttered under her breath, Alice made very little of this confrontation. Such was Alice’s fear of someone else sitting in her seat that when I interviewed her she insisted that we remain in the lounge for that reason.

For Isobel, possessions, home and not having to ask anyone else appeared to be intrinsically linked symbols of independence and autonomy and a means of expressing identity:

‘You should have your stuff where you want it, for the night, handy, and that’s it finished, don’t ask anyone else. That’s the way I feel. [pause] I’ve got you into the that’s helped me, because I’ve got the location to get the bus place place. And that’s I’ve got it. So I still got it and keepley good. I

wish I was home, though. In Glasgu town.'

[Interview, Isobel MacDonald].

Isobel clearly did not feel that she had her personal possessions and this was important to her, just as it was to those who guarded possessions and territory. Stripped of these and of familiar roles played out during a lifetime's experience, a sense of self can be difficult to maintain. It may be gained by the institutional image presented, but is almost certainly to be a changed self. This has also been the experience of prison inmates and they have been seen to offer effective means of resistance to it (Fox, 2001). Used as a method of self-preservation, self-reform is feigned to project the image that rehabilitation and remorse has occurred. Self and resistance will be discussed more fully in Chapter 9.

A sense of having a territory and sitting in the same seat was often confused by the constant rearrangement of furniture in Lavender Wing of Deer View Grange. It was something I asked the Deputy Matron about and she told me it was to facilitate interactions. When the furniture was rearranged it particularly seemed to upset Susan Stirling. Susan liked to sit in one area of the lounge: she also seemed uncomfortable if this was on a settee where she had to sit in close proximity to another resident. When she could not find a seat that suited her requirements, as often happened when the furniture was rearranged, she would come into the lounge, shrug and go out again. She would do this several times and must have walked some distance to keep repeating the exercise. On one such occasion she had been into the lounge several times looking for a suitable seat and eventually sat on a small stool that I often used to sit with residents.

Interestingly, this was met with much indignation from both Alice and Isobel, who now saw this as Susan sitting in my designated seat.

There is also a sense of injustice if residents from another wing come to Lavender Wing and start interfering with possessions. On one evening a resident from another wing came in and took away the waste basket. Alice and Rebecca Jackson united on this and joined forces to regain the property which they clearly believed was theirs. Lavender Wing is their home and the lounge is their sitting room. In the absence of personal possessions they had a strong sense of public possessions belonging to them.

Within this group living and surveillance culture, it would be hard to imagine that Susan's search for familiarity in the lounge should go unnoticed by staff. In fact, I searched their faces for reaction. Each time I did this, with various staff, there was a turning away and concern to be busy with what Gubrium termed 'bed and body work' (1997), the visible work of presentation.

Surveillance

Presentation is a large part of surveillance culture of nursing homes and an indication to those exerting the gaze that routine is being followed and this is indeed a caring environment. Beds are made, crumbs vacuumed up and clean tidy residents delivered to the lounge of Lavender Wing according to

a regular schedule. This is the work of 'bed and body' (Gubrium, 1997; Henderson, 1995). That Betty MacRobert should be dressed in her best clothes for her husband's visit was an indication that presentation is important. It was also noticeable that on Saturday mornings and party days, when more family visitors may be expected, attention to presentation of residents was prioritised. On these occasions, the most noticeable addition to residents' appearance was in the application of jewellery, make-up and more careful arrangement of hair styling. These symbols not only showed care but individuality and a sense of personal identity.

How residents were presented did clearly impact when they had visitors:

Jimmy's sister stayed chatting to me while Jimmy was eating his lunch. She was clearly worried about him as he had to go for a hospital referral because a 'patch' had been found on his lung. Jimmy's sister visits briefly on most days. She said it was nice to see him in a 'collar and tie' today. (CA1) had dressed him up, and his sister commented it was 'like the ol' Jimmy'.

His presentation seemed to be particularly significant for Jimmy's sister in view of his illness. It gave the appearance that Jimmy was being well cared for. Appearing to be a genuine effort by (CA1) to convey this and to make Jimmy feel good about himself, it also showed concern for his personhood. As suggested by Kitwood (1997), it conveyed emotional consideration and a positive marker for the relationship between Jimmy and his sister.

Presentation then, had more purpose than satisfying the surveillance culture. It was important for family visitors too. When Dorothy McIntosh's niece visited, she always checked that she was wearing jewellery and if it

was missing would go to her room to fetch it. In view of this importance to visitors, I was surprised by the lack of wedding rings worn by residents. The wedding ring depicts perfection in the circle and unity of the married:

Like gold to aery thinnesse beate.

If they be two, they are two so
As stiffe twin compasses are two,
Thy soule the fixt foot, makes no show
To move, but doth, if th' other doe.

Donne, 1976: 20.

In Donne's terms the symbolism of the unity in marriage persists beyond the death of a spouse. In residents' terms also, but I never heard reference from the five widows in the study to the death of their spouses. Sometimes residents would suddenly notice their wedding ring was not there and mention this to me. Care staff were often present when this occurred, and dealt with it in a similar way to unwanted emotions, by turning away and becoming busy with something else. I did not ask about or learn the reason for the absence of wedding rings, but it was clearly something that was, at times, significant to residents.

If possessions give a sense of identity, personalisation and individuality, the lack of them in public areas produces universality. This is also the case with surveillance, which is a key part of nursing home culture. Nobody within or visiting from without escapes the gaze. Just as Foucault (1991) describes in the Panopticon, surveillance can be conducted by anyone and is conducted by everyone. Staff watch residents and residents watch staff. Different levels of staff, residents, inspectors, visitors and researchers all

engage in and are subjected to scrutiny. The purpose of this observation varies according to position and the forces of power and control.

Each time I visited Deer View Grange, I sat and observed whatever passed before my eyes, aware from the questioning I received that my presence also attracted attention from residents and staff. Never was this more apparent than the day I broke the rules. On a few occasions when I had spent time with Isobel MacDonald she had asked if I had a camera and would take her photograph. With naivete, enthusiasm and a certain amount of affection for the residents in my study, after conducting taped interviews one day I produced a camera from my bag, and after carefully asking those residents concerned, started to take snapshots of them. I felt these people had become my friends and my purpose was to please Isobel and other residents by taking their photographs and to have residents' pictures to inspire me when I wrote about them. Just a matter of minutes passed before I was approached by the Deputy Matron, drawn to one side, and reminded that there was nothing on the consent forms signed by relatives giving permission for me to take photographs of residents. Initially I was shocked at my own stupidity and later that news of my infringement had travelled so quickly. My professional and personal pride had been severely bruised by this incident and through it I was reminded of my place and the boundaries which must not be traversed. As I reflected on the situation and thought more broadly around it, I gained a sense of how pervasive surveillance is in nursing home life. It may occur for differing

reasons but through an hierarchical system of reporting it ultimately becomes a means of control.

If I felt the gaze was upon me I was not alone in this. Staff were often defensive towards me and keen to point out what they believed were good nursing home practices. One morning, I went into the lounge of Lavender Wing while care assistants were busy getting residents up and dressed. Six residents were already in the lounge and I sat next to Jane Gilbert who took my hand and started chatting to me. We were sitting like this when a care assistant brought Myra Bains into the lounge, in a wheelchair. This care assistant, upon seeing me, froze on the spot saying 'Whoops I didn't know you were there'. She then went on to say that she had done it all wrong allowing Myra's feet to drag on the floor rather than having them on rests, and had also left her teeth out. It emphasised, for me, how much this care assistant, used to the constant surveillance occurring in the nursing home, also believed that she was under surveillance by me.

This sort of reaction was not confined to care assistants, as a Senior Nursing Officer similarly justified her actions on another occasion. Again, I was sitting in the lounge of Lavender Wing. Most residents had been taken into the dining room and the care assistants were serving breakfast. Jimmy McLean was sitting in the lounge hoping to have a cigarette before breakfast when the Senior Nursing Officer came in and started to reprimand Jimmy about an outing to the pub on the previous evening. I left the lounge soon after this and was on my way out of the building when the

Senior Nursing Officer hurriedly caught up with me, saying she had not seen me in the lounge and also that she thought she should explain to me what had happened. This was an interesting reaction to what she must have imagined to be the power of my gaze whilst she was clearly exercising her authority over a resident.

Infantilization

Residents were most obviously under constant surveillance, a practice shrouded in the auspices of medicalization by such rituals as charting bowel movements and general comments on their health. This regular toileting and the lack of privacy provided by this daytime communal lounge living forms the basis of what could be seen as infantilization: 'treating older adults as if they were children' (Lyman, 1993: 68). Through restricting choice and autonomy, dependency or excess disability is fostered. When people have dementia, the tendency may be for this to happen more than to other people in nursing homes. The fact that people with dementia often forget recent events may sometimes be exploited through empty threats and promises.

The bodily needs of people with dementia living on Lavender Wing are well met by care assistants. It is a very clear signal that this is so when residents are clean, tidy and smelling of perfume rather than bodily emissions. Visitors, inspectors and senior staff can also easily observe these signs of good care. Less readily detected by surveillance is

emotional care. It is also more difficult to deliver in a detached way. This will be discussed more fully in Chapter 7: Emotions and Dementia.

To return to infantilization practices, there are examples that can be drawn from my fieldwork. When residents are upset they are often told that they will get a visitor later, or that their relative will be telephoned on their behalf. If Rebecca Jackson wandered a lot, or started saying she missed her father, she was often told that someone would be visiting later. For instance I was sitting next to her one day:

She was very sad most of the time. She was worried that she hadn't got any money and said several times if she had the money she'd 'just go away'. She mentioned several times that if she could go with her mother it would be okay. She also seemed to be expecting her son to visit [after prompting from CA16 who really had no idea whether he was coming or not].

Surveillance could be seen as the determinant and the result of power and control in nursing home cultures. Power and control could also be seen to determine the amount of choice and autonomy that residents have. The lack of privacy and possessions in the public areas of Lavender Wing are symptomatic of this and the efforts to enforce a collective group rather than autonomous individuals with self identities requires standardisation. Consistently with Goffman's 'total institutions' small numbers of staff can control a group, and deviance from uniformity is easily detected 'against the visible, constantly examined compliance of the others' (Goffman, 1991: 18). Infantilization similarly is symptomatic of this culture and reflects of this dominant ideology. It is indeed such an accepted part of the culture that comments such as 'It's like having the wee ones again' (Care assistant preparing for Halloween Party) were commonplace.

Power and Control

One issue that illustrates how power and control are often abused in the nursing home culture is that of smoking, encompassing choice, autonomy and infantilization. It is one to which I shall return in Chapter 9 in relation to rules, rule breaking and resistance, but is worth outlining here.

There is a ruling within Deer View Grange that smoking will take place within a designated area at designated times while staff are present to supervise. This designated area is Lavender Wing. Most residents who smoke do not keep their own cigarettes, Jimmy being the exception to this. No resident keeps a lighter or matches. Thus, smoking is controlled by staff and risk of fire minimised.

I witnessed several occasions when staff control of smoking was used as an abuse of power (which I will discuss in Chapter 9). Another aspect of residents smoking on Lavender Wing was that of choice for non smokers, many of whom were immobile, whom I never once heard consulted about whether they wished to stay whilst people smoked. Three residents, on separate occasions, also complained that they were cold because the windows were open to let smoke out (Rebecca Jackson, Dorothy McIntosh and Isobel MacDonald).

It is difficult to accommodate all wishes when the lounge is the focus of all activity and residents are kept together in a group. The issue of smoking also, I believe, shows how untenable it is when people have been used to a lifetime of autonomy and choice.

Staff emotional strain

The surveillance culture of the nursing home can be a stressful environment for staff. It may be that the discourse of the institution, as Douglas (1986) suggests, means that the nursing home virtually thinks, but this can be in conflict with the interests of individuals within it in a similar way that projecting a corporate image conflicts with the emotional interests of airline stewardesses (Hochschild, 1983). The emphasis, in Deer View Grange, upon bed and body work leaves staff with little preparation for the emotional strains that can occur for them. Although I never interviewed them about it, staff often spoke to me about the emotional strain of their work. For instance, (CA25) talked to me about the emotional strain of the work, saying she did not know if she would be able to continue when she married in 18 months time. Another care assistant talked about her feelings when residents die. 'It's the worst thing about the job' she said. She also went on to describe what it had been like when there were several deaths in Deer View Grange and how difficult she had found it that families were grateful and saying things like 'Thank you for looking after our mum' and hugging her. She found that really hard.

This sort of emotional turmoil that care assistants experienced would probably explain why some tried to stay more detached from residents. On one occasion one of the most experienced care assistants on Lavender Wing spoke to me as if she had no feelings for residents yet I had always seen her being kind and spending time with them. She told me that she had done care work for about eighteen years because she could fit it in with bringing up her family by working nights. Individual care assistants had responsibility for what was called 'wardrobe duty' for one or two residents where they made sure they had toiletries and the clothes they needed. The Deputy Matron had led me to believe that there was therefore a close relationship between residents and the care assistant doing their wardrobe duty, so I asked her about this. She told me that it was no stronger than with anyone else and that she just did her job.

This care assistant was undoubtedly denying her feelings either to me, in the interests of maintaining the discourse of the institution, or to residents by acting out kind responses. This is the sort of emotional conflict that Hochschild (1983) described occurring for air stewardesses when they projected a company image, and smiled and hid their own emotions. It is also a part of the culture of nursing homes.

Conclusion

Through constructing a typical day in Deer View Grange a description of nursing home routine has been revealed. The routine, developed within a

medical model framework, assumes residents to be passive recipients of care. Like other institutional settings there is a concern with group control, which in a surveillance culture exposes deviants from compliance. This culture is so pervasive as to allow surveillance of all within, including monitoring of efficient use of staff time. This impacts upon presentation and causes staff time to focus on work that can visibly be seen to be done. Internal personal conflicts for care assistants, arising out of emotion work they do, are not so apparent.

The culture of nursing homes can infantilize residents and exert power and control over them, reducing them to child-like status, with no autonomy. Rules are an integral part of maintaining routine, efficiency and group control. They do not necessarily operate for the benefit of individualism and positive self images. Lack of personal possessions similarly disadvantages individualism and self identity. However, the appearance of compliance within this culture may mask resistance; residents like prison inmates may feign group identity and passivity by active concealment.

It has been shown that the environment of the nursing home can be thought of as a surveillance culture. Governed by routine, efficiency, power, control and rules, the emphasis is on 'bed and body work' and the product is well presented residents. This impacts upon the potential opportunities for individuals to interact in relationships, there being no privacy to see visitors and long hours in the company of others. These

may or may not be others that individuals would choose to relate to. The environment may, in fact, encourage withdrawal and resistance.

The discussion in this chapter has set the environmental context for the three substantive analytical chapters that follow. It has demonstrated what a strong impact nursing home cultures can have on residents, staff and the relationships between them. Many of the topics that have arisen will continue to appear throughout the remaining chapters. Staff emotional strain has been mentioned briefly: residents' emotions are the topic of the next chapter.

Chapter 7: Emotions and dementia

If we are to see residents as active social participants three ways in which this could occur are through emotions, in interactions and in boundary definition. These could be thought of as three spheres of social awareness emanating from the self: intimate, shared and generalized. These require social competence and specific indicators of this may be found in defining self, significant others and a generalized other. They are all pertinent to relationships: for instance the self is defined relationally by obtaining a 'looking-glass' image (Cooley, 1998), by referring to real or imaginary others in 'reference other orientation' (Kuwayama, 1994), or in narration to and including stories of others. These others may be significant others from the present or past such as mothers or spouses, or a generalized other perhaps constituting everyone in Lavender Wing lounge.

The first aspect of the active social self to be discussed is the most inner and intimate, usually only revealed in backstage performances. This is the emotional self. A range of emotions was talked about and expressed in the ethnography, some related to dementia. 'Social support' (Hochschild, 1983; Phillipson *et al*, 2001) is a part of this, an aspect that may often appear to compete with the interests of a surveillance culture as described by Foucault (1991) and Goffman (1991).

The majority of participants in the study had over 70 years of life history and experience behind them which formed their personal biographies.

Dementia is also a part of this, but a small and recent addition to the profiles of these individuals. Kitwood recognised the uniqueness of each person who has dementia and advocated a new culture of care:

... respectful of what they have accomplished and compassionate to what they have endured. It reinstates the emotions . . . It emphasizes the fact that our existence is essentially social. Kitwood, 1997: 135.

This chapter is about emotions expressed and talked about by participants in the study. My aim is to explore the extent to which residents experienced emotions and if so, whether this was a social experience or not.

Residents' emotions

Dementia, emotions and the nursing home culture were a part of everyday life in Deer View Grange for residents. Emotions were experienced within the context of interactions and relationships. When everyday life is confined to living in a nursing home these interactions are influenced both by the culture and those with whom one is engaging in such relationships, be they people within the nursing home, in the mind or oneself.

Trying to understand another person's subjectivity concerning emotions is not straightforward. They may talk about emotions, or say how they feel about something. This can give part of the story, but as in any interactions, there are additional clues that tell more. Body language and facial expressions reveal a lot, for instance nervous fidgeting, an anxious look on the face or one of pure pleasure, as can hesitation, laughter and tears. As

with social cues described by Goffman (1970) and Strauss (1997), cues to emotional feelings are given out and detected automatically by culturally socialized individuals. Thus, in the course of my fieldwork I did use my intuition, along with other observations and knowledge that I already had learnt of residents, to set what I detected in context. This I considered, in a similar way to Blumer's methodology, to involve using sensitizing concepts in a 'logic of discovery' (Meltzer *et al*, 1980: 67).

The purpose of this analysis is to explore the extent of active social participation by residents on an emotional basis, within the context of relationships. What follows is a range of emotions talked about and expressed by research participants. The headings under which the emotions have been placed are my attempt at categorizing the essence of their expression, though initiation of the actual emotion always came from residents. I have included along with these quotations from interviews [shown in single quotation marks], or a paraphrase of what is contained in my fieldnotes. Some emotions clearly related to the experience of dementia and are discussed separately in relation to three aspects of dementia; confusion, wandering and awareness of dementia. Additionally, I make some comments on staff reactions to emotions and whether, as part of broader social support, residents are given emotional support. I have selected this range of emotions on the basis of them arising during the ethnography; they are discussed in alphabetical order.

Anger: 'They think they're the bosses'

Though not shown, expressed or talked about frequently, when anger did occur it was a clear and strong emotion.

IM: Yes, aha. I used to get on with them, you know. But she doesna bother very much at all. But I did get off with it all the same. Th th that happens you know, our place they used to go out often and that one, and its no' fair, its no' fair really. However, they do it. They think they're the bosses the whole damn thing. Makes me angry sometimes, which is no use. I don't worry myself. I don't worry myself and I do worry myself. And I've seen sometimes I'm a greetin but you know, just for a while, it comes on to me and I get angry.

GM: What about, Isobel?

IM: Some of the things they say, you know, and then there's the what do you call it . . . everyone comes in here and then a lot lot lot [a care assistant suddenly turns the music up very loud, Isobel is distracted, and the conversation ceases temporally].
[Interview with Isobel MacDonald]

At the stage when Isobel had been distracted she had grown very angry. It was unclear if this was concerned with a memory from her past or something that she was angry about in the present. Whether this was about something real or imaginary it was real for Isobel at this time. I do not know if the distraction was deliberate: as it was one that I witnessed being repeated many times, I believe that it was. It indicated a means of staff detaching from Isobel's emotions just as staff had done in Luske's (1990) study in a psychiatric ward. It also indicated a failure to provide 'social support' which has been seen as a 'buttress' in the aetiology of depression (Brown and Harris, 1978).

Someone who frequently showed anger was Susan Stirling. This was inward anger, clenching her fists, beating her hands down against herself and shrugging as she scolded under her breath. It appeared to be shouting

in whispers at either herself or others that she imagined to be there. It may even have been rehearsal for what she would have liked to say to others.

I was also guilty of angering Rebecca Jackson one day. She had apparently been up all night and she slept until just after tea time [probably 11.30am]. She tried to get up immediately but was very sleepy. I tried to get her to stay seated until she fully awoke, but this angered her and she said 'I don't know you'. I backed away and she sat of her own accord. This anger in Rebecca was a means of resistance to dependency: as Phillipson *et al* (2001) pointed out, older people are keen to maintain boundaries in order to maintain continued independence.

Care assistants could similarly be insensitive and cause anger in residents. For instance, (CA7) took IM off to the toilet, not first asking her if she wanted to go, or even telling her, but just saying 'We're going for a walk'. (CA20) also went in. I was extremely surprised to hear a huge commotion break out from IM and then from the care assistants. When they came out she was again very pale and also very angry, so angry she looked ready to hit out at the care assistants [she was shaking her arms at them]. This was really out of character for IM. Kindness, time, explanation and training might have prevented this completely. I also felt that (CA7) could be quite intimidating because of her size. She lifted all residents unaided so obviously also had a lot of strength.

Amusement: 'Surely you'll be sober sometime'

Verbal communication was restricted for some residents in this study, though I often believed from facial expressions and flashes of recognition in the eyes that much understanding had been retained. Part of these non-verbal communications were also emotional expressions. For instance, an amusing moment may be shared. Dorothy McIntosh communicated with difficulty, most language being lost to her. She was asleep in a chair in the lounge one day when her teeth fell out of her mouth and shot across the room. She woke with a start and looked surprised. When her teeth were returned to her she laughed with what seemed to be amusement and embarrassment giving the care assistant a little hug of gratitude. Laughter can signify both amusement and embarrassment, but Dorothy's facial expression and the little shrug of the shoulders accompanying this were signals of both. It was interesting that it was within the interaction between them that Dorothy and the care assistant were able to share the funny side of the situation and dispel any discomfort that may have arisen. It showed 'a kind of social bargain' (Lofland, L, 1978: 44), where embarrassment and threat to selves were easily dissolved.

As researcher, I was also the source of some amusement. When I conducted taped interviews with residents, they believed it to be a strange thing for me to want to do. They often laughed at the idea of it. Laughter was also frequently spontaneous during interviews, which sometimes meant that either residents understood what they had appeared not to, or they had picked up social cues, which allowed definition of the situation

(Strauss, 1997: 48-49), from me and others around that laughter was about to be initiated by us. Whenever I tried to do a taped interview with Rebecca Jackson it was because she was particularly chatty with me. However, every time I switched on the tape recorder she would become silent, walk off or perform to the tape rather than continuing conversation. Perhaps this was another form of resistance. She would often just say a short phrase such as 'I never' or 'We didnae' and then laugh. Isobel MacDonald joked with me at the start of an interview one day:

GM: I'm going to get a stool and pull it across. [pause] Put it here shall I?
[pulling a stool across next to where Isobel is sitting and sitting myself]

IM: How do I get you for it, sober? Surely you'll be sober sometime.
[laughs]

GM: [also laughing] Do you think I'm drunk then?

IM: Oh dear, oh. I hope to see you sober, it doesnae matter what time it is.

[we both laugh joined by the care assistant]
[Interview IM]

The strangeness of the situation for Isobel could be justified if I were drunk, and therefore behaving strangely. The laughter could also deflect from mistakes made in the interaction and in this case covered Isobel's uncertainty about whether she had defined the situation in the same way as I had. Goffman (1963) suggests that these errors do occur in interaction, such as using a wrong word or mistaking a social cue. Effective and collusive strategies are usually employed to correct or gloss over these. They could also be accounted for in the sort of corroboration suggested by Lofland, L (1978), and laughter would be an effective and active strategy.

Anxiety: 'I've nae money'

Laughter often spread amongst residents, as can be seen happening in all social groups. The social group is acting as a generalized other, by which individuals reference themselves (Mead, 1967: 154). In a similar way to the spread of laughter, anxieties could also spread between residents. When one resident became worried or expressed that they feared something this often also had an impact on others. When it became windy and Rebecca Jackson voiced a fear that the parasol on the patio would come crashing through the patio doors both Alice Taylor and Isobel MacDonald started to worry about this. This also happened when a resident said that they wanted their mother, a significant other, in later conversations on the same day several participants would mention their mother. Rebecca Jackson often spoke of not having money and on the days that she said this to me others would also voice this concern. Worries seemed to spread amongst residents much more than positive emotions, perhaps giving rise to the notion that staff needed to exercise control over residents' emotions for fear of 'emotional contagion' (Lee-Treweek, 1996: 123). But I also observed other times when some residents put on what could be described as a united front against care staff to engage in rule breaking. This will be discussed more fully in Chapter 9.

Some residents expressed anxieties about personal safety. Isobel MacDonald spoke to me of being afraid for her own safety 'It's terrible to be threatened constantly' she said. This was said a few days after Alice Taylor had also said 'It's a terrible place for your safety, I've never known a

place like it'. I believe these remarks were referring to threats from different sources. Alice did behave as if she felt threatened when she guarded her territory from other residents and as she sat and thought of this, the threat became real in her mind. Isobel spoke of feeling threatened shortly after insensitive treatment by care staff, an issue that will be discussed later in this chapter. These sorts of anxieties may be common for older people or for people living in residential care, and are perhaps an indication that they perceived themselves as vulnerable. It could also suggest a vulnerability associated with the surveillance culture, resulting from not having privacy.

Compassion: 'She's in a bad way, that's a shame that'

Compassion for others was an empathetic reaction displayed by some individuals, interestingly, the same individuals who were quick to condemn if they thought this was warranted. This indicated that both compassion and condemnation might be emotional responses. One resident to which this applied was Jimmy McLean who showed great compassion to others, who wandered and performed fake cleaning movements. Conversely, he would sit and discuss how fat a care assistant was who had refused to give him a light for his cigarette. One day (Thelma), another resident from Lavender Wing, came very close to Jimmy and chattered right into his face. Far from getting annoyed as I had expected, he teased her and laughed with her kindly. He talked generally of others on another occasion saying 'Of course they can't help it, that's the way they are'. When another resident approached the two of us one day he said 'She's in a bad way,

that's a shame that, to see someone like that'. Jimmy also seemed to be able to take the role of the other to visualise a situation. In much the same way as I would ask him about his life and family he asked me of my family and I talked to him about my father who had died a few years previously. He was interested, wanted to know what sort of a man he was and expressed sadness that he was no longer alive. This sadness was a response to my own feelings and again one that surprised me. I had not expected such empathy from someone who was so quick to criticise. It also demonstrated to me that Jimmy was very competent at slipping between frontstage and backstage performances, at one time presenting entertaining frontstage bravado then changing to backstage disclosure and confiding.

Characteristically, Alice Taylor, who was fiercely protective of her property and territory in the lounge, would frequently call others 'besom' or 'bitch' when she believed the comments were deserved. Yet Alice also surprised me by the compassion she could show for others. When she read the paper one day there was news of a small boy who had been killed, she told me. Alice had two daughters and often spoke of them when they were children. This clearly helped her take the role of the waiting mother. She then went on to speculate on how his mother would feel 'waiting for him to come home from school'. Another incident, early one morning, also showed how compassionate she could be:

When Jane Gilbert was wheeled into the lounge her chair was placed next to Alice Taylor . . . They were probably together about half an hour in all, with care assistants busy in bedrooms. I remember thinking 'I hope Jane

isn't in a hitting out mood because she could easily get Alice, which would not please her at all'. What in fact happened was that Jane called out a few times. Alice started comforting her, telling her it was alright. Then she started holding her hands, saying one was hot and the other one was cold, she rubbed them, even caressed them. Jane did then hit Alice a few times and Alice just responded by more comforting. Jane spoke to Alice and Alice, rather than saying her usual 'I don't understand what you're saying', replied sympathetically.

These examples do show emotional responses of compassion. They show empathy, competence and the ability to take the role of the other and gain 'sympathetic introspection' (Blumer, 1986), as is only possible for socially active participants. They may also be a means of distancing from those they see as having dementia and indicative of some awareness into their own dementia conditions. This is something I will develop further in the discussion on emotions and dementia later in this chapter.

Excitement: Having a good hair day

Excitement was rare among the residents in this study. Interaction between Susan Stirling and myself was similarly rare. Upon my arrival one day Susan came and sat next to me and chatted excitedly. It was a Tuesday and the hairdresser was in, although Susan was not having her hair done. Her conversation was focused on hair and an incident she remembered from her childhood when her hair blew up in the wind. This led to a conversation on the weather and the past, all initiated by Susan, very animated, rapid and quickly over. It was as if this excitement allowed Susan to express herself and to communicate when otherwise she would not have done so. It was not an easy conversation and I felt guarded in

case I disturbed the flow of interaction, or responded in a way that would inhibit Susan.

Happy: 'Hallagallum'

The energy of Susan's excitement and the guarded way I had felt I needed to engage with her left me feeling uneasy, in contrast to when Isobel was in a happy mood. Isobel MacDonald was a sociable lady who loved nothing better than to sit beside someone with whom she could have a conversation. Within Isobel's interactions a range of emotions were shown and talked about, often entwined with stories from the past. When engaging with the present Isobel often chanted a rhyme:

Zinty tinty hallagallum,
The cat went out to get some fun,
He got some fun,
And toad islum,
Zinty tinty hallagallum.

All the staff and I had been taught this rhyme by Isobel. We all also knew that when she chanted it she was very happy. This was an expression of her joy. This was clearly so as she smiled broadly during the recital and talked about things such as, how 'nice it is' to be here, 'what a lovely view there is' from the window, and 'isn't it a glorious day?' before and after the recital. For Isobel being happy was really about the joy of being in a social situation, having someone with her to chatter to and not feeling isolated by sitting alone. Sitting alone for Isobel could signify loss.

Loss: 'Who'll pick up memory talks of me?'

Loss has frequently been spoken about in relation to dementia and is shown in the characterisations of dementia, for instance in fictional and press representations, as already examined (Chapter 3). It has been written about in relation to the loss of self (Cohen and Eisdorfer, 1986) for the person who has dementia. For the people in this study there were some losses, though I found no evidence of the loss of self. It was clear from some conversations with residents that as they had got older, their roles had changed, those roles that are defined in relation to others. For instance, their significant others were not living with them now, so their roles as for instance wife, mother, and carer, had less prominence and it was difficult for most to play the passive role of nursing home resident.

The losses I witnessed were often tangible or lost roles. Isobel MacDonald, who loved to sit and chatter, had lost some hearing, sight and the ability to play the piano. When she did reflect on this she said she wanted her mother, father and brother. There appeared to be a sense of security to be gained from these significant others. She sometimes spoke of not knowing where people had gone, with reference to people from her past, but I also witnessed the upset she felt if people from the present left or were taken away without explanation. Care assistants were keen to tell me that Isobel MacDonald and Dorothy McIntosh were friends and they also often sat them together in the lounge. Yet, after they had been sitting together chattering it was not unknown for the care assistants to take Dorothy away from Isobel without explanation, leaving Isobel alone and calling after them.

This clearly upset Isobel and she did not understand what had happened. I do not think that she realised that Dorothy had not deliberately left her for some unexplained reason. It may even have made her relive previous losses she had experienced when significant others had died.

When I interviewed Rebecca Jackson it was clear she lost people, words and places. These excerpts from one interview serve to illustrate:

RJ: Don't ken where mae faether went, ken?

GM: Where did you think he was?

RJ: Oh I could speir [means to ask or enquire]

[Long pause]

[Interview with Rebecca Jackson].

RJ: Oh God! [spoken wearily, looking towards her feet]

GM: What's the matter?

RJ: Eh?

GM: What's the matter?

RJ: I just want my . . . [hesitantly tries to get another word out but seems to be struggling and gives up]

[Interview with Rebecca Jackson].

RJ: Oh we'll go up here and then just . . . that wee just er, that wee bit there.

GM: That wee bit there?

[long pause]

RJ: Well I think we'll away round this corner.
[starts to get to her feet]

GM: I'll give you a hand Rebecca.

RJ: What? No. You go away ken. I don't know where to go.

[Interview with Rebecca Jackson].

This indicated that just because Rebecca was unsure of where to go it did not mean that she wanted to relinquish her independence. It echoed Crane's (1999) homeless people and Stephens' (1976) single room occupancy tenants: those who had chosen alternatives to living as dependants with their children. Thus, by refusing help to get up from her chair, Rebecca was denying dependence and actively resisting the environment in which she now lived.

These excerpts were all taken from the same interview with Rebecca, but the most poignant phrase was said when I was about to end the interview and go home for lunch:

GM: Well I think I'll away Rebecca. Are you away for your lunch?

[Long pause]

RJ: Leaving again. Nothing. All the people going by and . . .

[I decide to stay. Long pause].

RJ: Who'll pick up memory talks of me?

[Interview with Rebecca Jackson].

Rebecca suggested her sadness that she was being left again, 'nothing' shows the emptiness of her feeling. Rebecca is a widow, with a large family who visit regularly and many staff in the Grange also know her and chat to her in passing. However, for her, everyone is always leaving, and always in a hurry: they are always busy and she has little to do. The question 'Who'll pick up memory talks of me?' could epitomise what it is to

live with dementia and be aware of it. I believe it meant who will do the remembering for me, and who will remember me? It asked many more questions for which I did not have the answers, and resounded in my thoughts throughout the rest of the research.

Love: 'Everything's right with them, no plasters'

Isobel did not have children, but often talked of her relationships with her husband, parents and siblings. She also often talked of people being in love and seemed to see everyone as being a part of a couple. Not always able to find the most obvious word, Isobel often substituted words with similar meanings and was able to maintain social competence in this way. When she talked of someone's relationship being good it had 'no plasters'. This is how she talked of love:

IM: Oh that was stupid, she's all right, she's all right now. That was the girl that lost everything, and then we got separated and now they're together again.

GM: Uh hum.

IM: And they really are in love with one another.

GM: Oh, lovely.

IM: It's everything's right with them, and no plasters or anything like that.

GM: And how about you, are you in love?

IM: I'm still like the fella and he knows, he's nice, nothing special loving, nothing about it, just pleasant and that's all. I'm very happy with him, and so is he's happy with me.

[Interview with Isobel MacDonald].

Regret: 'I'm fed up with it'

It was almost a catch phrase for Isobel to say 'I'm tired, are you tired?' She often spoke of being tired, but this following passage from an interview was more than this. There was also accompanying these words a very strong sense of disappointment and regret.

IM: (pause) I'm tired all the same. I wish I was . . . life was better then then we could just enjoy our days as we used to do. But we cannae do that now.

GM: Why not?

IM: Well, you've to watch the time you take the gam gam business to watch this this and you watch the next thing before you can take it on you. Ah I'm fed up with it myself, really.

[Interview with Isobel MacDonald].

Disappointment that better times have passed were accompanied by regret and a longing to be in a different place:

IM: I wish I was home. I wish I was home, not just in my garden, but at home at home. I wish I was home, there.

GM: It's nice to have the company here Isobel.

IM: No, it's no', it's no' company. It's just I'm really done out, what with one then the other, one and other, sometimes it gets my nerves. I think I better go home sometime and get away, away from it.

[Interview with Isobel MacDonald].

Some less articulate residents also expressed regret. Jane Gilbert was chatting away and nobody listened to her. I saw her stare into space and say 'What's your name?' When (CA7) and (CA16) approached her to take her through to supper she said 'Sorry'. This theme of regret seemed to stay with Jane on this day. Whilst I could understand little of what she said, very clear apologies were made several times to anyone who came near to Jane on this visit. Perhaps her regret was that everyone ignored her. More

probably she had an 'inner conversation' (Mead, 1967: 141) with herself or others from the past or present, real or imagined (Mead, 1967: 143), in which she expressed regret.

Dementia and emotions

Dementia is difficult to diagnose, being confirmed only at autopsy by identification of changes that have occurred in the brain. All of the people in this study are thought to have a dementia condition because they have experienced behavioural changes consistent with dementia. Confusion and wandering are two such behaviours and can be accompanied by strong emotions. Similarly, awareness by the person that something is wrong, even if they are not aware that dementia may be the cause, can evoke emotions. In this section I shall discuss confusion, wandering and awareness of dementia in relation to emotions.

Confusion: 'Come along in, [to my room] it's okay, she's out'

Confusion is commonly associated with dementia and there are many examples of it that I can draw from my fieldwork. It can be distressing for the person with dementia and observers of the confusion. In addition to the distress, other emotions also seem to accompany confusion, a frequent one being frustration. This would usually be the case if the confusion were

something as simple as forgetting the day of the week. This example comes from my fieldnotes:

When I asked him if he'd been out last night he said 'No', and then looked a bit puzzled asking what day it was. Jimmy usually went out for a drink on a Thursday night, when on this Friday morning I had asked about this he wasn't sure if he had been or not but clearly went through the reasoning that if it was Friday morning then he may have been. He then made an excuse that he had to go, and hurried away from the lounge with a grimace on his face.

Time was often a factor of confusion for participants in the study, ranging from not being sure of the day of the week, to mistaking the subject's own age and to confusing different family generations. So whilst Alice Taylor frequently checked the time on the clock throughout the day she repeatedly overestimated her age, and talked of her children as if they belonged to the same generation as herself and her siblings and also her parents' generation. On some occasions, Alice would pass these comments off, unaware of how she fused generations together, and on other occasions she would become flustered, say 'No, that can't be right' and then seek verification of her facts from whoever she conversed with. She often sought reassurance in this way, but people did not always give it: they might not have known the 'correct' version of the story. This was when Alice would get angry, place the blame on the person who had failed to help and try to get them to leave her alone. Then she would sit quietly and try to work things out for herself.

In the same vein, the passage of time had ceased for Rebecca Jackson, when she showed me a photograph of herself in which she did not recognise who the person was. She looked familiar to her. It could be her

mother she reasoned, but did not look quite like her. As Rebecca tried to recall who this was in the photograph, she seemed to despair, frustrated in the attempt. I saw Rebecca about two hours after this, she still carried the photograph and looked at it from time to time, still puzzling as to who it might be. Interestingly, during a visit to another nursing home in the region, the Nursing Officer told me that people with dementia had failed to recognise their current images when they had been placed on their bedroom doors as an aid for them locating their own rooms. When they had been shown photographs of themselves as much younger, these were the images which they did identify as being themselves.

The 'mask of age' (Hepworth, 1991) is a familiar concept; that people as they age still feel the same as when they were younger and are shocked to see a mirror image of an older person. If we are to follow Gubrium's (1986a) argument that dementia is a normal part of ageing, then dementia would be the ultimate and final mask of ageing. Dementia is pathologised, perhaps because it presents all the worst scenarios of ageing and correspondingly becomes the most exaggerated form of ageism.

If, under the mask of dementia, residents fail to recognise their own mirror image, other people's identity may also be confused. One of the residents had not been seen in Lavender Wing lounge for some weeks due to an illness requiring bed rest. Upon her first appearance, Alice Taylor approached her asking how she was and saying how nice it was to see her

after so long. Later Alice told me that she and the other resident had worked in the Shell Factory together. Similarly, Isobel:

IM thought that RJ was her husband today. The two chattered about what they should do and comings and goings in the lounge. IM was according to (CA9) when (SN4) was round 'very agitated today'.

I found this a very surprising comment, as I had witnessed nothing to suggest that Isobel was agitated. Whilst there may have been good reason that I was not aware of for this suggestion, I found it very disturbing that care assistants should make judgements and report to the medically qualified Staff Nurse, on a matter that appeared to be more related to emotion than health. However, Isobel had believed Rebecca to be her husband.

As I became a familiar figure at the Grange, I was also often mistaken for someone else, my own identity apparently changing to fit the situation. To Alice Taylor, I was the traveller who recorded our conversations to play to my family later. To Rebecca Jackson I was 'Nettie' a close and long-term friend. Dorothy McIntosh looked me straight in the eyes one day and said 'I know you', seemed very pleased at this but could not remember who I was. Isobel MacDonald believed me to be a different person at different times, and yet was also sometimes surprised that I knew her name.

These cases of mistaken identity almost always led to disappointment, as the person believed to be someone from the past failed to behave and respond as expected. At other times they seemed to satisfy a wish to see and be with that person and produced accompanying pleasure. When this

occurred it showed it was not only important to know people, but that in addition to being with this generalized other of Lavender Wing lounge, day in and day out, it was important to be with significant others. Just as in interactions with others social competence is maintained strategically, when significant others are missing, strategy is also employed. When significant others die, they may be replaced with new significant others, or they may be recreated in the interaction process with the self, to adjust everyday life to what it has been in the past. This is an emotional and an interactional act, it is a part of relationships, and for some residents in this study, I believe it was used as a way of making sense of everyday life.

An example of how confusions may occur together is recorded in my fieldnotes:

RJ was in the corridor near reception today when I arrived. She immediately said to me 'Hello, I haven't seen you for a while, how are you?' [It had been a week since I'd been in]. ... Later RJ came down to the lounge; she was worried, she couldn't remember her name and she didn't know her address. I took her along to her room and we carefully read '10, Rebecca Jackson'. She recognised this and went inside taking me with her but saying 'Come along in, it's okay, she's out'.

There were multiple confusions for Rebecca on this day and whilst she was obviously worried she showed no other emotion. Within about an hour of this however, Rebecca was very upset and came to the lounge crying, looking for reassurance and an explanation.

Harré (1986) points out that emotions are strategic. They are also active and arise out of interaction (Burkitt, 1997). Rebecca had arrived at the point where confusion led to emotions via social interaction. Throughout

this confusion, Rebecca had maintained social competence, employing strategies and asking assistance to do so. In this way she was able to maintain a degree of independence. Only after all these strategies had failed to provide explanations and reassurance did Rebecca get upset to the point of crying. This was when she sought emotional support from care staff. As this appearance in Lavender Wing coincided with the arrival of the tea trolley, Rebecca was given a cup of tea. Soon after this her son arrived to visit her and she was able to sit and talk to him, gaining her reassurance from him.

Wandering: Desperately seeking something

Spatial confusion also occurred within Deer View Grange. Residents might become lost or imagine the surroundings to be somewhere from their pasts. Residents walking along the corridor often referred to this as 'going up the street'.

Of the nine residents involved in the study, five were mobile and able to walk unassisted. Of these five participants, all were involved in what may be described as wandering at one time or another. There were frequent emotions accompanying wandering. They often followed a regular pattern, that is, manifested in the same way repeatedly for particular individuals.

Rebecca Jackson frequently met me in the corridor of Deer View Grange when I arrived on a visit. Sometimes she would walk to Lavender Wing

with me, and if she did, would usually turn away to walk back the way she had come. Rebecca was a local lady coming from the same community as many of the staff, she was known to them and met them in their comings and goings in the corridor. On occasions, Rebecca's walking took the form of relentless trudging until she was exhausted and could not continue. This was when tears and disappointment accompanied her wandering.

On other occasions Rebecca was concerned that she needed to get her 'messages' [a Scottish term for getting the groceries], frequently naming particular items such as eggs that she needed. She also worried that she had no money. Her wanderings were sometimes concerned with this quest. The corridor outside her bedroom she called 'the street'. Unfortunately, this wandering for Rebecca often ended in upset and disappointment, when she turned the corner of the corridor and did not recognise the place. It was like a longing to be back in the familiar surroundings of the street and to have something to do connected with running the household. Rebecca Jackson spent many hours wandering in this way; sometimes she would say something that suggested she might be lost such as 'I don't know where to go'. This could also be attributed to not knowing how to find the way to a place she was looking for. This was likely, as she always seemed to know where the lounge, her own room and the entrance were.

Alice Taylor walked with the aid of a stick. Being mobile she usually went to the toilet, into the dining room and along the corridor without aid from

care assistants. She was often accompanied when she needed reassurance. An example of this was her weekly visit to the hairdressers, which required negotiation from the lounge beyond her own room and around a corner in the corridor. Alice liked to take a walk a few times a day to prevent herself becoming stiff from sitting. This walk was unaided and usually did not extend as far as her own bedroom. When Alice did visit the hairdresser she often appeared unsettled and confused upon her return to the lounge. On several such occasions she demanded her coat be fetched, and when it arrived she would put it on and sit in the lounge waiting. We talked about visiting the hairdresser during taped interviews and she told me where the salon was situated in the High Street, that she caught a bus to get there and that she always visited her mother on the way back. In Alice's mind this was the ritual that she still went through when visiting the hairdresser. Her Tuesday wanderings after having her hair done in Deer View Grange were seeking the bus, her mother's house and her home.

On one occasion Isobel MacDonald also confided in a backstage intimacy to me that she had got lost coming back from the hairdressers. I had seen her trying different bedroom doors off the corridor and when I called out to her she asked for the way to the lounge. Isobel did wander when she was upset. When coding incidents of this in my fieldnotes, I categorized it under what I termed 'desperately seeking something'. This was an all-encompassing phrase that covered all aspects of being unsettled, trying to work something out, or looking for something familiar. It was closely

associated with confusion and more often than not resulted in emotional upset later if the 'something' was not found.

Seeking a seat, when the furniture in Lavender Wing lounge was rearranged, was a major quest for Susan Stirling (as I discussed in Chapter 6). However, during the nine months of my fieldwork at Deer View Grange, there was a marked decline in her social skills. I witnessed a change from an independent though withdrawn individual to one totally dependent on others to tell her what to do, when and where to go. By the end of my fieldwork Susan could not find her way from the lounge of Lavender Wing to the adjoining dining room. She did not know where her bedroom was or what time of the day she should go there. Accompanying this change in Susan was a frequent wandering of the corridor, not knowing where to go or why. This wandering did not fall into the 'desperately seeking something' category, because Susan did not appear to be desperate to find anything, she just wandered aimlessly and apparently unemotionally. Any emotions seemed to focus inwardly and communication appeared to be more often with herself than with others.

Susan's changed behaviour, and what I considered were concealed emotions, could easily have been interpreted as a 'loss of self'. If the model of disease and decline were applied, this would almost certainly be the conclusion. However, a clue to how I perceived Susan, and how I perceived other residents, rests in the relationships that I had with them. I was never able to build a relationship with Susan, though I witnessed

others who did. My failure to connect with her impacted upon the way that I perceived her. I did not learn what her emotions were, my interactions with her were restricted. Susan's sister had described her as 'withdrawn'. This was part of her personality, it was nothing to do with dementia, Susan was and always had been withdrawn.

Jimmy McLean wandered less frequently than others. He had daily visits from his family and his mobility usually centred around walks with them and getting to and from his room to the dining room at meal times. When Jimmy often wandered was when he was upset about something. This would focus on an injustice such as being told he could not have a light for his cigarette because he had not eaten. Such an injustice would prompt him to go backwards and forwards between the lounge of Lavender Wing and the Reception area of Deer View Grange asking for someone to give him a light for his cigarette.

I have described these mobile residents as wandering, and illustrated the difference between wandering accompanied by emotions and just taking a walk. Some wandering accompanied by emotions may be more attributable to the environment in which they are living rather than to dementia, as is the strong desire that many had to get out of the building. In many conversations with Alice Taylor, Rebecca Jackson, Isobel MacDonald and Jimmy McLean there was mention of feeling locked up and of wanting to leave. For example:

I arrived to RJ trying to get out to catch a bus. I walked the corridor with her for about 45 minutes. She was exhausted and had been pacing all morning. I left her because I did not feel I was helping and that she might follow me to the lounge if I did. Shortly after this the Receptionist telephoned Lavender Wing for the care assistants to collect RJ because she was afraid she was in danger of collapsing.

Other residents also echoed this desire in their attempts to get out of the building. This note following a conversation with Alice is representative:

I'm struck by how people are always trying to get out of the home, and AT comments that it's like being a prisoner - it can be quite literally like being a prisoner, physically not being allowed out without an escort [Diary entry].

It also left me wondering if it was the building from which residents wished to escape or if it served as metaphor for dementia, an ageing body or the social institutionalisation of ageing. For as Blaikie points out:

... deep old age may be replacing death as the great contemporary taboo ... Institutions effect both temporal and spatial segregation ... old age is now regarded as the appropriate time to suffer specific maladies prior to death and the old people's home is considered the appropriate place. Blaikie, 1999: 195.

If this image exists, it may also exist for institutionalised people who do not want to be dependent and held in an appropriate place. Surely such bleak images of prospects ahead would give rise to the strong impetus to get out. Wandering is often seen as problematic in association with dementia and it is not, however, restricted to the institutional environment. Bayley (1998) talks of Iris Murdoch wandering from home, when she had dementia. In my visits to residential and nursing homes for people with dementia, prior to the start of fieldwork, I encountered one home in which they had put 'wandering paths'. These enabled residents to wander out independently, the path would twist and turn and always end up back at the door. So, it seems wandering is a recognised element of dementia. What I hope is also apparent from my fieldwork is that residents often wander when they

are upset. If people with dementia do this, then other people may also do so, and wandering becomes behaviour associated with dementia or being upset.

Awareness of dementia: 'I don't really want to be classed as just a person as this ... I would rather be classed a different place'

So whilst some people who have dementia may wander, the fact that they do may also be associated with being upset. Undoubtedly some of this upset may be due to anger and frustration at confusion arising from memory problems caused by dementia, or by awareness of the dementia condition. This awareness of a person's own condition may be revealed in conversation with them. A certain amount of awareness that something may be wrong often accompanied confused periods. It appeared to also become apparent at times when residents were calm, quiet and reflecting on life. Three simple comments from the same day are of this type:

'Something's wrong, I don't know what'. [Jimmy McLean].

'I like talking to people because when I'm not on my own I don't feel stupid'. [Isobel MacDonald].

'I get annoyed with myself that I can't remember things'.
[Alice Taylor].

These did appear to be comments made without emotion, just clear statements of fact. Awareness that something was wrong could be a part of a group of worries expressed:

IM was temporarily troubled. She worried about who might be ill, she fretted about going home. The telephone rang in the lounge and woke her - she was troubled about who was on the telephone, and why they had rung if they didn't have any news. The most memorable thing she said was 'I don't know what happened to make me like this, I don't remember. I want to go home, but I don't know how'. I started showing her the magazine, I picked on large pictures but she said 'I can't really see because I'm upset'. She elaborated that she was upset that she couldn't remember things, knew something had happened, but didn't know what and always felt tired. Eventually she fell asleep, totally worn out.

Whilst Isobel was upset about many things the core of her worry seemed to centre around a certain amount of awareness of dementia. 'I don't know what happened to make me like this', shows this awareness though it may not have a name. Dementia and living in a nursing home were clearly not what Isobel wanted, as this comment from an interview shows:

IM: I don't really want to be classed as just a person as this ... I would rather be classed a different place.

[Interview, Isobel MacDonald]

She does not want to be classed as a person with dementia, she does not want to be here and this place defines her as a person with dementia. I did not see inside Isobel's bedroom, so do not know what personal possessions she had that would help her identify this place and her life. Within the lounge of Lavender Wing, where most of our interactions took place, there was nothing. But this reference to being 'classed' also signifies how she is seen by others. She does not want to be classed like this, she does not want to play the role required in this place and she does not want this image of 'a person as this' reflected back to her. This all shows social competence and awareness of dementia. Though Isobel may not express it in these terms it shows awareness of labelling, of gaining a 'looking-glass' self and of the importance of place for identity. Like the

phrase of Rebecca's 'Who'll pick up memory talks of me?' this stayed with me throughout research. It summed up the sadness of being old, powerless and institutionalised.

Often awareness of dementia would follow a confused period. Alice Taylor liked to sit and talk about her life on occasions. In the telling, she would often ask if what she was saying was right. This sometimes formed a rhetorical question to herself but more frequently would be directed to a care assistant, visitor or myself. Each retelling of a story would be a rehearsal and confirmation of who she was. After a period of considerable confusion one day, when Alice was brought back to the lounge in tears because she had got lost, she said this to me:

AT: I shouldnae have lived this long. I'm 98 or 100, I don't remember. Fancy forgetting your age. I forget, I lose things, I go to look for things thinking they're missing and they're there all the time. It's not the same when you get old you know... I never thought I would end up like this. I wish I was all right.

There was considerable sadness from Alice in this conversation and awareness that she was not all right. I have already discussed how compassionate residents might be to others who were showing behavioural symptoms of dementia. This was also a time when a certain amount of awareness into an individual's own dementia would occur:

Alice Taylor was today talking about 'others' quite a bit. She talked of another resident getting away with and doing what they liked. She watched another resident come quietly into the lounge and sit down saying 'she's another one. It's sad when they get like that. It's a good job we don't know what's in store for us'.

There was with this almost an acceptance and inevitability. At other times I felt it might also be a denial and means of distancing from dementia, by role play as a care assistant:

This 'honorary care assistant' role does seem to occur a few times. I remember AT behaving similarly to JG. It also seems to be a way of distancing the self from dementia and saying 'Look I'm really not as bad as this person I'm caring for'. For JM, banter with care assistants probably plays a similar function, but he also shows a great deal of awareness of his own condition at times. Being aware doesn't necessarily mean that you don't want to distance yourself from it, of course! Having awareness of the dementia condition of others is also often met with a great deal of compassion, and there have been times when I have heard this from JM, AT and IM. The nursing home situation potentially parades all the possible conditions of the future, some awareness of this must be upsetting and depressing for residents, particularly if they already have some awareness of their own condition.

The residents who talked to me most were those who appeared to be aware that something might be happening to them. Rebecca Jackson's 'Who'll pick up memory talks of me' and Betty MacRobert wondering why she was always tired were probably also flashes of being aware. Others who communicated less also showed emotion that might or might not be related to awareness of their own condition.

Emotional support

Responses to residents' emotions were not always supportive. Time pressures on care staff and the focus on bed and body work sometimes precluded emotion work taking place in this setting. Staff undoubtedly experienced emotional stress themselves as already discussed (Chapter 6). This may have caused them to distance themselves from the people

they cared for, finding it easier to work with a certain amount of detachment.

When staff did react to residents' emotions it was often more in the interest of preserving the culture and keeping control of residents. As Lee-Treweek found in her study of care staff, they held a common belief that 'older people needed to be monitored emotionally by others because they lacked control over their own emotions' (Lee-Treweek, 1996: 123). I found in my study of people with dementia, that attempts were made by care staff to control residents and their emotions. This was frequently done by taking advantage of the fact that residents might have short-term memory problems and in the interests of pacifying the present situation, rather than considering the long-term well-being of individuals. This practice is infantilizing (Hockey and James, 1993; Lyman, 1993) and reduces residents to child-like status: it denies the social and emotional competence that they clearly display.

Within the group and surveillance culture (Goffman, 1991: 18) of Deer View Grange, which required residents to spend long periods in public view, any emotional expression by residents occurred in the full view of staff. There were times when residents would express concerns and worries. Staff responses depended very much upon the skills and personalities of individual staff and also upon the time, patience and emotional competence that they had available.

Some situations could be difficult to deal with, when residents would take no consoling. This is an example with Rebecca Jackson:

RJ was in a distressed state and would take no consoling. The care assistants said she had been up most of the night. She kept asking for someone to show her 'The way out of here'. She wanted to see how her 'faether' was and also her mother. She asked for money for the 'phone to call her mother. She kept saying 'Everyone just looks at you and won't help'. She cried a lot and I sat with her. She stopped crying when she had a cup of tea and biscuit, this seemed to take her mind off things and I couldn't help thinking if she had something to do that it would be easier for her.

When tea was served, it often presented an opportunity for care assistants to communicate with residents naturally. Helping Dorothy McIntosh with a cup of tea offered such an opportunity, and would be as important for her in emotional terms as it was in providing fluids, because of the limited communication she had.

Residents did get upset at times and needed comforting from staff who were often able to do this with a few reassuring words, a hug or a touch. When this failed other resources were drawn upon. One common practice was that the music would be turned up loud so that care staff could not hear the resident. Another ploy was to exploit the fact that people with dementia might not remember promises later. These might be that a relative would visit soon, or that the care assistant would telephone a relative on the resident's behalf. These were promises that rarely materialised.

The most distressing practice that I witnessed in terms of social support was that of preventing residents from expressing their emotions. This

example of this happening with Isobel MacDonald is taken from my fieldnotes:

The other major incident of the day was IM bursting into tears. She had been seated on the two seater sofa with (June) alongside her. (June) just got up and walked away leaving IM alone. She was upset at this and wanted someone to go after her. I went and sat next to her. She protested to me about (June) leaving, saying it wasn't right. Then (Lillian) and (CA23) were dancing to the music and IM just burst into tears. I cuddled IM and as soon as (CA17) realised what was happening she came over. IM said it was a bad memory that was upsetting her and should she tell her about it. (CA17) said 'no' to forget it. IM said she just wanted to cry and cry. (CA17) was concerned that she shouldn't. So IM was stopped from talking about what worried her and stopped from crying - this seemed wrong to me and was going against all my instincts. I stayed with IM for some time and she chatted to me, though she remained very sad.

Effectively, Isobel's emotional voice had been silenced. A conversation I had with her nearly two months after this suggested that she did find it upsetting not being able to talk emotionally:

IM slept most of the time during my visit. She has not looked well or appeared happy for quite a few visits now. She sat in a chair on her own. I went and joined her at tea time and her chatter was severely restricted [for Isobel]. She did say 'I'm tired', she did say 'I wish I was home' and she also said 'It's no good in here, there's no chance to say what you think'.

This matter concerned me greatly and I wondered if professional counselling was available to residents. I asked the Deputy Matron about it in interview and she told me that there was enough nursing expertise within Deer View Grange without drawing on other resources. This is an interesting stance, firmly defining the boundaries of the Grange.

Before concluding this section, I should like to mention my position as researcher in relation to support to residents. There were times when I also felt upset and angry during my fieldwork. I often felt inadequate and ill equipped to offer emotional support to residents. My examples of how to

cope were set before me by the staff in Deer View Grange. A tape recording made three months into the fieldwork revealed that I was becoming part of this environment:

GM: And you've always got a smile on your face haven't you? [This is me trying to get a smile on her face and doing it exactly the same way as emotion work is often done in the Nursing Home - I didn't even realise until I heard the tape!!]

[Interview with Rebecca Jackson].

The culture is so pervasive operating at a subconscious and everyday level, that it is difficult not to become a part of it.

Conclusion

Within this ethnography residents talked about and expressed a range of emotions, some of which appeared to relate to the nursing home culture and others directly to having dementia. Emotions reflect the inner active self, the intimate, often engaged in backstage performance, and this research shows that participants were active at this level. This dispels former claims that the self is lost in people with dementia.

Emotional cues, like those in interaction, are used in everyday life to help define a situation. Competence in sending and detecting these cues could clearly be seen amongst residents. The amount of compassion and empathy for others expressed by residents is evidence of this. It also showed a capacity to take the role of the other and adopt an attitude of sympathetic introspection.

The social group of everyone in Lavender Wing lounge acted as a generalized other by which individuals referenced themselves. This facilitated the spread or contagion of some emotions, notably laughter and anxiety.

Under the mask of dementia residents may have failed to recognise a mirror image or a current photograph of themselves. They also often mistook the identity of others. This may have been a means of replacing significant others who had died. Significant others, particularly mothers, were associated with security and this was demonstrated in their being repeatedly mentioned at times of anxiety and confusion.

Three aspects of emotions relating to dementia have been analysed. People in the study did experience confusion, sometimes accompanied by emotion, but not always. They showed that they were aware of dementia in others and in themselves. This sometimes prompted emotional responses and other times it did not. Mobile residents frequently wandered and this appeared to be more prevalent when they were upset.

Emotions are strategic, active and arise out of interaction and it appears that social competence and strategy can accompany periods of confusion. Rebecca used these as a means of retaining some independence, seeking limited assistance on her own terms, rather than relinquishing total control.

From time to time during this research, residents provided me with the most poignant, all inclusive quotations. Two most notable ones arose in the course of emotional periods for residents. Rebecca Jackson's:

'Who'll pick up memory talks of me?'

may voice all our concerns and fears of dementia, until we also hear from Isobel MacDonald that institutionalisation may be worse than dementia, in:

'I don't want to be classed as just a person as this ... I would rather be classed a different place'.

This emphasised the importance of place when experiencing everyday life and the impact that it has on the experience. It was also associated with the impetus to get out of the confines of the building, which was often displayed in wandering. This may have served as metaphor for wishing to leave dementia, an ageing body, or the socially institutionalised setting of ageing and dementia. Residents clearly expressed awareness of dementia in others and themselves. When referencing dementia in others it served to distance themselves from it.

Staff responses to residents' emotions were often to silence their expression rather than to offer support. They might tell residents to forget what was troubling them, drown out their words by increasing the volume of music, or simply ignore them. The voices of the residents' emotional selves time and again were silenced. Care staff spoke to me unprompted about the emotional strains of doing their job, yet they seemed less able to take the role of the other than residents were. However, I realised how pervasive and persuasive the culture of the nursing home could be, when I

found myself engaging in similar emotion work to care staff, of cajoling and distracting till the moment passed. This practice is infantilizing; reducing residents to child-like status. It is a means of social control and is part of the surveillance culture.

This chapter has contributed to the thesis by showing the first aspect of active social participation of residents in this study. The emotional self engages in intimacies and is also presentational; most often backstage, but also frontstage; seeking significant others, and responding and performing to a generalized other. Like interactions, emotions are strategic and active, they have been seen to arise out of relationships in interactions. They help individuals make sense of everyday life and position themselves in relation to others. This is a process that continues in interactions, the sphere of the active social self to be discussed in the next chapter.

Chapter 8: Interaction

Residents involved in this study have been shown to express and talk about a range of emotions. They also seek social support and specifically emotional support as would be found in a confiding relationship (Brown and Harris, 1978; Phillipson *et al*, 2001). This was the first aspect of the active, social self to be discussed and one considered as intimate and backstage. The second aspect of this active social participation is involved in interactions. Some of these are also backstage and intimate, but there is a progression towards more formality associated with frontstage performances. This is where ritual and social competence are displayed.

The emotional self is seen as the innermost, and more of the self is disclosed in interactions. The interactional self is sometimes displayed as emotional and at other times much less so and in the more 'presentational' way suggested by Lebra (1994). The self is also constructed and reconstructed in interactions with others. Such categorization involves definition of significant others and a generalized other. Only active social participants could achieve this.

A number of questions arise out of the analytical focus on interaction. Who do residents interact with? What do they talk about? How do they do it? These are sections for discussion in this chapter under the subheadings of 'people', 'content' and 'form'. Interweaving questions of time and purpose into each subsection covers the issue of when and why interaction occurs.

During and as a result of fieldwork a new area of examination arose that I had not previously considered. It concerns the way that research participants maintained and demonstrated social competence, through rituals associated with greeting others, taking turns in conversation and saying farewells as people departed. This is an apparently paradoxical area to examine when participants have dementia and may have language impairments, as it moves from the area of interaction, where we look at how actors relate to each other, into the area of conversation analysis. Through interaction, the form and processes which give order, are considered, but conversation analysis is also concerned with the form of interactions. This will therefore be introduced under the section relating to 'form' of interaction.

An important contextual factor concerning interaction is that of the nursing home culture, already considered in Chapter 6. This does impact, as it did in emotional expression, upon the opportunities that arise for residents to interact. As Willcocks *et al* (1998) pointed out, there is an opportunity for interaction created by the company of other older people, but residents may not wish to be in a situation where they have to converse with them all day long. It is a restrictive environment both in terms of the surveillance culture structured by routine, and of being bounded and confined.

Specific features including the noise of getting work done, of lounge music, seating arrangements and lack of privacy which can disable interaction and

exacerbate hearing impairments, chaos and confusion. The confinement of residents to the physical bounds of the building also limited whom they could interact with to those who came in, except on those occasions when residents might be escorted out. Despite these obstacles when the opportunities were presented several residents enjoyed sitting and engaging in interactions. There are three elements of these that I would like to discuss, the people they are with, the content and the form.

People

Within the restrictions of the surveillance culture of the nursing home there were opportunities to interact with 'people of the present ... of our own imaginings ... of the past' (Mead, 1967; 143) and with the self. The purposes of these interactions varied between negotiating everyday life in Deer View Grange, gaining interesting news, friendship and self-definition or identity. According to the purpose of interaction whom one engaged with in conversation would be strategically important.

Of interactions with others, staff were most frequently engaged in conversations as they were there the whole time. However, when visitors came to Lavender Wing, with the sole intent of seeing a resident, the resident was usually able to engage in a more concentrated conversation. Many visitors were family members. Amongst the other visitors were friends, doctors, a priest and myself the researcher.

Visitors

Gubrium discussed how having visitors could privilege residents because of the 'prestige associated with having routine ties' (1997: 97). This was because residents then became a source of news from outside of Murray Manor and therefore could engage in conversation as a means of conveying this news to others. In Deer View Grange having visitors also appeared to carry a certain amount of prestige. This prestige had a positive impact upon the relationship between residents and staff.

If visitors were expected, care staff would pay particular attention to the presentation of the resident(s) concerned. This was apparent at the Christmas party when many visitors were expected and another example is drawn from my fieldnotes:

Betty MacRobert looked lovely today, dressed in really pretty clothes I had not seen before. (CA9) said she had dressed her in a skirt and blouse by mistake thinking it was the day Betty's husband visited.

This presentation of residents would serve two purposes, that of making the resident look as if he/she were well cared for and also creating a tangible prompt to residents that they should anticipate a visitor. This focus of attention from staff was not restricted to preparations before the visit, as when visitors did arrive, staff often, in this surveillance culture, liked to be seen to be paying attention to the resident being visited. This would take the form of prompting residents to tell their visitors what they had been doing and how they had been looking forward to this visit.

After residents had received visitors their prestige sometimes continued as other residents and staff made comments on their visitors and discussed how nice it had been to see them. For instance:

Rebecca Jackson had a visit from (VRJ2) who is married to her son. Rebecca told everyone in the lounge who it was after she had left and Alice Taylor and Betty MacRobert commented what a nice girl she was.

In this way, a visit lasting an hour may privilege a resident for much longer, when anticipation of the visit and discussion of a visit that had taken place is added to the visiting time.

Despite this extended attention to residents surrounding visits from outside Deer View Grange, everyday life continued within for 24 hours a day. Those within were therefore the source of more continual interactions with staff and other residents. The purposes of interactions with both differed sometimes and at others were the same.

Staff

My observations in this research were confined to the public areas of Deer View Grange and I therefore did not witness what interactions occurred whilst intimate body work took place. Many of the interactions I did observe between care staff and residents occurred at meal times, when tea and biscuits were served, and whilst residents were assisted from lounge to dining room and so forth. These were times of ritual and routine and were mainly concerned with frontstage interaction. The relationships were very clearly of differential power, with residents in a position of dependence

upon care staff for everyday needs. Some care staff were more prone to exploit this position and infantilize residents than others, generally in the interest of maintaining control of the group. Much more of this will be discussed in Chapter 9 on Boundaries.

Staff did at times sit and chat to residents, which might be thought more backstage interaction, though it often appeared to be in the interest of being seen to be doing so, for the benefit of nursing home inspectors, families and senior staff. Thus the presentation of the conversational image was an aspect of staff surveillance impacting upon interaction. When staff were not engaged in other duties they more frequently interacted with each other, which apparently was genuine backstage chat and probably a necessary release from the emotional labour of caring and indicative of the 'emotional ties between staff' (Lee-Treweek, 1996: 122).

Residents did often choose to engage staff in conversation for purposes other than negotiating everyday living. These were bound up with self definition, distancing from others and from dementia. In these terms they were strategic (Goffman, 1970) and demonstrated social competence. At other times they were concerned with seeking emotional reassurance as opposed to bodily requirements.

Isobel, Rebecca, Alice, Susan and (Rosie) were all looking for someone to reassure them. They felt confused when care assistants weren't there to reassure them. The care assistants had been on duty since 7.30 am, when they came into the lounge shortly before my 7.20 pm departure they both looked exhausted and they had to give this reassurance that only those in the uniforms can.

Staff seemed to give more attention to residents when they were coherent:

Jane Gilbert was quite lively and coherent and consequently got more attention from care assistants.

than when they were confused:

Isobel MacDonald was confused when she returned from the hairdressers. It's sad because when she feels like she does today, which is aggrieved and wanting to be home, it can be easier not to sit and have a chat with her. This is often what happens with care assistants - if someone keeps saying they want to go home or that it's terrible the way they've been treated it is easier to ignore this than try and reason or listen.

As in all relationships, the benefits were not always exclusively experienced by residents. This care assistant described how much pleasure she sometimes gained from residents:

Myra Bains seems to be brilliant and alert just now. (CA17) was telling me that a couple of days ago she had a bit of spare time and offered Myra a 'soak in the bath' [she usually gets a shower on Saturday evenings]. (CA17) told me how much pleasure this bathtime gave her because Myra so obviously enjoyed it. She lay back and kicked her legs and (CA17) sat with her chatting. (CA17) had very definitely enjoyed this experience, an intimate moment with Myra.

So, care assistants and residents sometimes shared backstage intimacies in interaction, a time when they would have acquired, if only temporarily, significant other status. The pleasure of this emanated from the sharing of the situation in the relationship.

Local People

Within Deer View Grange many residents and staff were local people and had lived in the geographical location for most of their lives. For these people there appeared to be a better understanding and empathy between staff and residents. For instance, Rebecca Jackson and her family had been known to local staff prior to her moving into Deer View Grange.

Rebecca needed regular reassurance at times of confusion and gained more immediate comfort from local staff than from others. She was also able to engage in rapid exchanges with these staff in a way only possible when there is a strong sense of shared meaning through shared history. The key to these relationships was in shared knowledge and in typifications, which did not require further explanation to gain shared understanding. They allowed gossip to be exchanged, which together with shared knowledge, dialect and understanding excluded those who did not share these (Gluckman, 1963).

Other residents who benefited from local connections and shared meanings were Jimmy McLean and Alice Taylor. As with Rebecca, both of these residents had regular visitors because of the proximity of Deer View Grange to their own homes. These residents therefore experienced regular visitor privileges as described earlier, which extended to a certain amount of loyalty from local care staff because of the relationships maintained between family and staff.

There is however, a contradiction and ambiguity in the relations of local staff, visitors and residents. They are all part of the same community in which people with dementia cannot be accommodated. Contradiction arises from nursing home residents being a part of that community yet separated from it. Ambiguity lies in where the boundaries are then seen to fall and in who actually determines them. This has relevance to issues to be discussed in the next chapter and will be taken up again at that point.

Residents

Relationships between residents were built on a different basis. When residents engaged in interactions with other residents the purposes seemed more closely linked with friendship and camaraderie. Examples of these are taken from my fieldnotes:

Susan Stirling and Alice Taylor were coming back to the lounge as I went away, I asked if they had enjoyed themselves. Susan said yes, Alice said 'no, I'm being honest'. The two ladies did, however, seem quite united through their shared experience of watching an old film musical and both smiled as they walked along together.

Neither Susan or Alice really socialised or appeared to have friends within Deer View Grange, it was the sense of a shared experience which made them happy to associate with each other on this occasion. Others were much more sociable and did have what could be classified as genuine friendship:

I have been told by care staff that Isobel MacDonald and Dorothy McIntosh are friends and have seen them sitting together but have not really witnessed any more than this. When I arrived today Dorothy was in a wheelchair and just going off to the chiropodist. Isobel was sitting on her own on the settee and (CA7) told her Dorothy had just gone off to get her feet done. In due course Dorothy returned and was seated on the settee next to Isobel. After a while they started to chatter. Much of Isobel's conversation was similar to those I have had with her. What was amazing was that Dorothy was genuinely searching for responses and replies. There seemed to be some reference to the seat, the floor and other residents who were wandering and both focused their attention on these together.

Isobel frequently liked to sit and chatter but Dorothy was much more impaired both verbally and physically. Both seemed to gain stimulation and companionship from this relationship. After this occasion I witnessed many other similar ones between these two friends. Within this relationship, as

with others between friends, there was a certain amount of social support and more specifically there was emotional support.

At times, care staff seemed to try and encourage friendships, for instance when a resident stayed at Deer View Grange for respite care, staff sat her with Alice Taylor. Similarly, when a younger resident moved into Deer View Grange she was brought to meet Betty MacRobert because they were closer in age than other residents.

Sadly, at other times the routine of Deer View Grange appeared unable to accommodate relationships. This was the case with the seating arrangements in the Dining Room of Lavender Wing. Dorothy and Isobel would be seated at separate tables at meal times, and even when Betty's husband visited and stayed for lunch he was placed at a different table from Betty. I do not believe this was as instrumental as being based upon potential disruption to the meal time. It was more likely that the subjectivity of residents, their feelings, emotions and desire to be with significant others could take only secondary place to control and surveillance of the group of Lavender Wing. In essence, personal choice could not be seen to override what was seen to be for the good of the group.

Self and imagined others

In the last chapter I talked about residents in the study mistaking the identity of others, believing them to be significant others from the past,

present and imagined. The number of instances of this occurring were frequent and often appeared to satisfy a need for residents to interact and be with that person. At other times they did lead to disappointment and upset, if the mistake was realised. Along with cases of mistaken identity were self interaction and interaction with imagined others.

As Mead has pointed out, thinking takes the form of internalised conversation and as in interaction it is a 'conversation of gestures' (1967: 141). In this study, internalised and externalised conversations undoubtedly did occur with the self. Often people would appear to be self absorbed. For instance, there are several accounts of this occurring in my fieldnotes involving both Jane Gilbert and Myra Bains, two residents whose verbal communication was restricted. Myra would often spend over an hour gently pointing to the buttons on her dress, as if either counting them or considering what they might be. I never saw her initiate a verbal interaction yet her responses to staff and myself always indicated a good understanding. Jane frequently called out to people and wanted to be touched and whilst she did respond to this touch, she rarely responded to pure conversation. Her interactions were with herself, with other imagined people, or people from her past. She did appear trapped within dementia and I believe I heard her make several references to her own death.

Susan Stirling often appeared to talk to herself or imagined others. Accompanying these interactions were shrugs of the shoulders and a great deal of tension. Susan rarely spoke to other residents, and favoured only

particular care staff, choosing to speak only to the people she wished to. When she did interact with care staff, or more specifically associate with them, this seemed to serve a particular purpose of both distancing from dementia and playing the role of honorary care assistant. Role play will be discussed later in this chapter.

Interaction with the self and interaction with imagined others takes the form of interaction with significant others rather than involving the generalized other of everyone in Lavender Wing lounge. It may often be internalised, and therefore intimate. It may often be shared.

Key points

The reasons for interaction for residents have arisen in different ways in this discussion and have differed according to whom the interaction has been with. Having visitors has been shown as a prestigious event, privileging the resident both in her/his presentation and in singling the resident out for interaction. The attention to presentation that residents were given when they expected a visitor, arising from the surveillance culture, helped prompt the resident that a visitor was coming. When visitors were present, staff further prompted residents to present a suitable impression to them. Within this ethos, additional attention to residents with visitors is also a matter which projects a favourable image to the visitors and an impression that this is what normally occurs.

When residents talked to staff it was often to seek help and support. Staff have the power to grant or deny this, which highlights inequalities in the relationships and the potential for dependency, excess disability and infantilization of residents, as suggested in the literature (Hockey and James, 1993; Lyman, 1993; Sabat, 1994). Residents also interacted with staff to aid self definition and to distance themselves from other residents and from dementia. This was strategic use of interaction and demonstrated the social competence of residents.

Local people shared backgrounds, dialect and knowledge that facilitated rapid interactional exchanges. These had shared meanings and did not require further explanations. They enabled definition of insiders and outsiders by exclusion of those who did not share meaning and were thus outsiders.

In interactions between residents the purpose was involved with friendship, camaraderie and shared experience. Staff encouraged these friendships, though they often appeared insensitive to barriers to them. Friendships may be a good source of social support. Yet again, the culture was often inflexible and did not easily accommodate different seating arrangements or threats to routine.

Residents did at times engage in relationships with the self or with imagined others. These appeared to involve either the self or significant others, rather than the generalized other of everyone in Lavender Wing

lounge. They were sometimes intimate, at other times shared; sometimes backstage and sometimes frontstage.

Having discussed whom residents in the study interact with I now look at what they talked about: at the content.

Content

Whilst other people were often involved in the interactions of participants in the study, they were also often the subject of conversations. Discussion would sometimes be about other residents, family, spouses, staff or friends. People from the past were sometimes talked about. Some of these references seemed to have particular significance for residents and are worth examining in more detail.

Mothers

There appeared to be a particular significance for many residents when they talked of their mothers. It often seemed to be associated with insecurity and confusion, and mothers were frequently believed to still be alive. They had clearly been significant others in the past and this status persisted. For example:

Alice Taylor was determined to go for a bus to see her mother. The care assistants kept coaxing her back to the lounge and to take her coat off. She appeared very confused.

At other times, when Alice recounted her life story, she talked of her mother in the past tense. She always spoke of her with great warmth telling how her mother had helped her to look after her children. Isobel often spoke of her mother, and always in the present tense:

I sat next to Isobel MacDonald and we had a similar conversation to the one the other day. She turned to me and said 'I'm not long back from Canada, you know'. She said she had come back because her mother was ill.

Isobel also spoke as if her mother was a part of her everyday life:

IM: Must write to my mother [Interview with Isobel MacDonald].

Rebecca Jackson often talked about both her mother and father in a way associated with her own security. She worried that she did not know where her 'faether' went and that she did not have the address of her mother just that she lived in Glasgow. She also spoke of getting a lift up to her mother's house because she had 'nae money' and her mother would help her out.

There were only three topics of conversation that Susan Stirling had with me, her mother, dogs and the weather. All were spoken about in a very matter of fact way, without the emotion expressed by many regarding their mothers.

Family, spouses and pets were also talked about often by residents and whilst they were obviously significant others from present and past, they did not appear to signify security in the same way as mothers did.

Those within Lavender Wing

A logical topic of interaction for residents was the people surrounding them and a part of their everyday lives. Staff were talked about sometimes in terms of mistaken identity; as someone remembered. They might also be referred to in terms of how helpful they were to residents, or how unhelpful. They were generally thought to be unhelpful when trying to enforce rules, a topic to which I will return in the next chapter.

On one occasion Alice spoke of staff as a means of defining herself in relation to them:

AT: Tall, she's tall compared to me [of student nurse], see she's tall too [of care assistant]. I'm a wee midgin [laughs]. Tall ones look, sitting there. They're nice lassies though. [Interview, Alice Taylor].

Association with staff was often sought by residents probably as a means of distancing from others and from dementia. I will talk more of this in regard to role play later in the chapter.

Other residents frequently became the topic of conversation for residents. The way they were talked about reveals a lot about the residents involved in the interaction. Firstly, other residents, particularly those showing visible behaviour associated with dementia, were nearly always defined as 'other'. In the same way as de Beauvoir described women being defined in relation to, and subordinate to men (1988: 16), this definition of other also describes other residents in relation to and subordinate to the self. It is a tool to distance from and deny presence in the self of dementia. An example:

Alice Taylor thinks most others are 'poor souls' - when someone from another wing came in she talked about 'that nuisance again'.

There could, as discussed in the last chapter, also be a certain amount of compassion for others, perhaps indicating some awareness of a resident's own dementia condition:

Alice Taylor was today talking about 'others' quite a bit. She said (Ruth) got away with and did what she liked. She watched (Lizzie) come quietly into the lounge and sit down and said she was another one, and 'It's sad when they get like that' and 'It's a good job we don't know what's in store for us'.

Alice Taylor was not unique in defining others, Rebecca Jackson, Isobel MacDonald and Jimmy McLean all talked of other residents at various times. This was sometimes with compassion and often with annoyance particularly if territory or property appeared threatened by residents from wings outside of Lavender Wing.

Talking about other people constantly helped define self identity in relational terms. I believe it helped people with awareness of their own dementia condition to position themselves relationally, and prepare for changes that might occur. Another topic of conversation, which also served this purpose, was that of death.

Death

Residents sometimes spoke directly about death and at other times less directly. As with opportunities to talk about and express emotions, death

appeared to be a topic that care staff would ignore or gloss over if residents raised it.

Many times I heard Jane Gilbert talk of her own death:

When I first arrived I sat with Jane Gilbert because she beckoned me over - she says a lot that I don't understand but she repeatedly says 'Please take me', I thought I heard her say 'dead' as well.

Jane's death became a preoccupation for her, but was also matter of fact and part of everyday chatter:

Jane Gilbert chattered away to me as she took her tea. I did not understand much but I did hear her say 'I'm ready, take me'. As I left her she also went into a parting routine, 'Take care, do come again', she said.

It was the context in which this was said that led me to believe that this referred to Jane's death. On this day I observed and listened to Jane for some considerable time, and I do feel that her utterings centred around death. This belief was further reinforced by the familiar reactions of care staff, that had been witnessed in relation to emotions, to turn away when they did not intend to become involved.

Much of Jane's interaction did seem to be with the self, or with imagined others, she also seemed to be talking in metaphor on this occasion: 'The light, take me to it, thank you'.

Interaction about death of other people was frequent in the recounting of life stories, of family members, and of friends, yet I never heard the death of husbands acknowledged even though five residents in the study were widows.

These are examples of residents talking about their own death:

Listening to, and transcribing an interview with Isobel MacDonald I have recalled something she said at a later discussion. 'I hope it goes quick' ... Is this a holiday she believes she is on, is the holiday a metaphor for the dementia she has become trapped within? If she wishes it to pass quickly, does she wish for an end to life itself? [Diary entry].

AT said to me 'I wish I was dead' - she was upset at the time about another resident sitting in her seat.

Rebecca worried - what if nobody knew she was here and she died, she asked me.

Rebecca Jackson was pacing the corridor and wouldn't stop. I walked with her for a time and she said 'If I don't get out of here I'm goin' to die'.

Isobel talked of a friend in Glasgow 'who just disappeared'.

I met Rebecca Jackson on the way in today, she said 'If I could only get a life [pause] you don't know what I mean do you?'

These examples do suggest, as with emotions, a need to talk about and prepare for death. When some of these were made I saw staff responses ranging from looking away to turning the music up. I never witnessed residents being encouraged to talk about death and I was sometimes left wondering if I had imagined or misinterpreted what residents said to me. But, I am almost certain from these staff reactions that what I interpreted was right.

Coping Strategies

Death did seem to be a subject that residents were able to talk about both directly and in metaphor, when permitted. But interaction did present

challenges to residents participating in the research if they forgot words, as was a common occurrence. It would often be an individual word or the name of an object that was lost. Two residents who were prone to this also used a most effective coping strategy of substituting words with similar meanings in order to maintain social competence. Rebecca Jackson frequently fought for a word, substituted 'thingymy' or 'whatsit' until others involved in the interaction assisted in the search. If the name for an object could not be found, Rebecca may describe its use, such as 'something to sit on' for a chair. Isobel MacDonald referred to a good relationship as 'having no plasters'.

Another example of the effective use of coping strategies to overcome difficulties with memory can be illustrated. Alice Taylor repeatedly told parts of her life story asking for verification from others that what she was saying was right. Each retelling reinforced Alice's biography and helped to (re)create her identity and self through the rehearsal of the narratives. Through the repetition of her stories, Alice was able to maintain a past by which to reference her present, along with social competence in everyday interactions.

There is almost poetry in the descriptions sometimes used in word substitution, a poetry arising out of the creativity to maintain social competence. Isobel said to me one day, 'They come here to tangle, you know'. She was talking about residents who had come to Lavender Wing from other parts of Deer View Grange, and as she continued to talk of

them, it became apparent that she meant they had come to socialise. The profound use of the word 'tangle' to refer to people with dementia who may have increased numbers of 'senile plaques and neurofibrillary tangles' in the brain (Jacques and Jackson, 2000:18), together with the reference to relationships, made this quotation from Isobel the ideal title for my thesis. Similarly, when Rebecca Jackson said 'Who'll pick up memory talks of me?' the meaning of the phrase goes beyond simply saying 'Who'll remember me?' and appears to encompass also the question of who will do the remembering for Rebecca as she is able to remember less. It does, like Isobel's phrase, encompass complex multiple meanings and show a greater social competence than may normally be employed in everyday life interactions.

Coping with interaction by means such as word substitution is strategic and a way of negotiation. Word substitution is a part of glossing, a strategy where meaning is not lost by gaining a general view. Interaction is co-operative, 'a kind of social bargain' (Lofland, L, 1978: 44), to maintain meaning in a situation.

Key points

Residents talked mostly about people, pets, routine and death. The amount of 'people talk' highlighted the importance of relationships with others from the past, present and imagined. The purpose of this talk of people was often concerned with seeking security and arose at confused

periods, as often appeared to be the case when talk was of their mothers. Talk of staff often sought to define the self relationally, or to say that staff members were helpful or unhelpful. Similarly, self images were defined and reinforced by talk of other residents, particularly when they were defined as 'other'. This also served to distance from the other resident and perhaps what could be detected of dementia.

A great deal of social competence became apparent in what residents talked about and this became particularly so when a word could not be remembered. Effective coping strategies were employed to compensate for these lost words and could give rise to very profound metaphorical statements. One of these, 'They come here to tangle', has become the title of this thesis. In this way the ethnography gives voice to participants in the study.

Form

Often as important as the words spoken in interaction is the form that interaction takes. In this section I want to give examples of how residents in the study used social form in their interactions. Form is concerned with 'movements, looks and vocal sounds' (Goffman, 1981: 2). It is subconscious, unintended, complementary to interactions and concerned with following ritual conventions.

Social cues

One way in which it was clear that residents were socially competent and active participants in interaction was in the way they picked up on and used social cues (Strauss, 1997: 48-49). Thus, even if full understanding of the words exchanged was not achieved, reactions and prompts were given at the appropriate times. For instance, residents frequently initiated laughter at appropriate stages in the interaction. If any understanding of language had been lost then this might depend on detecting intonations in the voice and body language of others involved in the interaction. This is what I believe happened on a number of occasions, an example of which was when Isobel believed me to be drunk and started laughing at my reaction to her suggestion before I did. The fact that Isobel initiated the laughter gave me a cue that it was appropriate for me also to laugh.

Isobel MacDonald did have difficulty with hearing and also had a certain amount of visual impairment, and because of this I always made a point of engaging eye contact with her and facing her when I spoke. This appeared to be an effective means of interacting with her. I realised how much Isobel relied on facial expressions one day when I was talking to both her and (Marcie) another resident at the same time. (Marcie) has very limited communication but laughs, smiles and nods a lot. I had found that a similar response from me seemed to please (Marcie). I was engaged in this exchange with (Marcie) whilst Isobel was telling me that she was not happy about something. Isobel then proceeded to say 'I don't think it's funny' and got very annoyed with me.

From Isobel's reaction to me I realised that she relies on facial expression, in interaction and is able to interpret them as appropriate or not. This was later backed up by an exchange between her and Betty MacRobert when she told Betty that she did not seem very pleased, as Betty rocked herself gently in her seat. Isobel clearly interprets facial expressions and body language and in this way is able to detect social cues.

Even for residents with severe language and communication impairments there were instances when there was evidence that social skills had been retained. The examples I want to draw on are welcomings, farewells and the sort of skills that would be put into use if entertaining a guest, making them feel comfortable and ensuring they had anything they needed.

Openings, Closings and Turn-taking

This is an area of the research that arose out of what I observed during fieldwork and consequently looked for similar evidence in the literature. Conversation is governed by rules which determine openings, closings and turn-taking (Strauss, 1997:80). These differ according to the situation. Goffman describes them as either 'unfocused interaction' where glances capture information about others, or 'focused interaction' occurring in open co-operation (Goffman, 1963: 24). The amount of ritual associated with each varies, for instance a group of people working or at home together do not need to formalise openings and closings (Goffman, 1963: 103), as they are in a 'continuing state of incipient talk' (Schegloff and Sacks, 1973: 325).

Throughout the fieldwork, I tried as much as possible to allow residents to approach me and to initiate interactions, with me taking a more passive role in the relationships. Physical mobility of residents sometimes meant that I needed to take more initiative in the interactions. However, an ideal opportunity presented one morning when I arrived in Lavender Wing whilst residents were in the dining room eating breakfast. I sat and waited in the lounge silently and eventually residents started to make their way in, some independently and others with assistance from care staff. Although I played a totally passive role, not attempting to catch the eye of any resident, every one of the nine participants in the study went through the process of catching my eye and either speaking, nodding or smiling by way of greeting me. Alice Taylor and Jimmy McLean, with whom I would often sit and talk in the mornings, were even apologetic that they had not seen me straight away. This is consistent with Goffman's notion of social recognition:

... there is "social recognition," namely, the process of openly welcoming or at least accepting the initiation of an engagement, as when a greeting or smile is returned ... Now, as previously suggested, in order to carry out certain forms of social recognition it will be necessary for the participants to recognize each other cognitively, or affect having done so, or apologize for not doing so.

Goffman, 1963: 113.

This is exactly what I found residents did when I waited for their initiation of a welcome. It was a skill retained by all research participants, whether or not they had lost some language through dementia.

Often residents were in the corridor of Deer View Grange when I arrived to start a fieldwork session. Always, if this occurred, I would be greeted. On one such time Rebecca Jackson was in the corridor near reception when I arrived. She immediately said to me 'Hello, I haven't seen you for a while, how are you?' [It had been a week since I had visited].

Whilst welcomes were usually initiated by residents, farewells were more responsive to me either announcing my departure or giving out social cues that I was about to depart. Some of these farewells were very straightforward as from Rebecca:

GM: I'll see you again.

RJ: Aye, cheerio.

[Interview with Rebecca Jackson].

Rebecca always managed a cheerful send-off for me even if she was not in a happy mood. However, one day after singing 'Cheerio' she continued by saying that she did not think she would see me again.

Much of what Jane Gilbert said was very difficult to understand and often appeared to be to herself or imagined others, but she also was able to launch into a clear parting routine when required, 'Take care, do come again', she said with an large wave of the hand. It did, as in this case, often appear to be an automatic response to my departure as it was at other times from Isobel MacDonald, Betty MacRobert and Susan Stirling.

Perhaps the most skilled resident at giving a good farewell was Alice Taylor. Even if Alice had previously been annoyed with me, as was frequently the case, perhaps because she had considered me unhelpful, or that I had not stayed long enough, she would perform the most elaborate routine upon my departure. She would tell me how nice it had been to see me, ask when I would be in again and cling to my hands before eventually giving me leave to go. I witnessed this leave-taking from Alice when she had family visitors and each time it was performed with the same vigour regardless of the significance of the relationship she had with that person.

Part of the 'organization of speaker turns' (Schegloff and Sacks, 1973: 289) is the way a conversation is brought to a close. Participants give cues when a conversation is drawing to a close that it is appropriate to begin a closing sequence. What specifically is being referred to is leave-taking rather than a situation where people remain together (Schegloff and Sacks, 1973: 325). This is not necessary unless a departure of one of the parties is to take place, so it really becomes a preparation for departure, or a cue from the person staying in place that it would now be appropriate to leave.

What Schegloff and Sacks term as 'closings' Goffman names as 'leave-taking' (1963: 110). In this, social cues give a suggestion that one party in the conversation wishes to be released. Detecting these cues, the other party issues leave-taking rights and allows departure. The exit cues, drawn from rules of etiquette, are initiated by the interviewer, giving the leave-taker the opportunity to make a reciprocating leaving speech before

departure (Goffman, 1963: 110-111). Thus, it is a co-operative act between conversational parties.

Schegloff and Sacks (1973) suggest that more preambles and preparation for closings may occur, which sometimes include the introduction of 'mentionables'. This may be a topic that one party was keen to introduce, but has not found the appropriate time during exchanges to do. A pre-closing sequence indicates that closing is soon desired and it is now time to introduce mentionables. These can then become part of the closing sequence, before 'terminal exchanges' take place (Schegloff and Sacks, 1973: 308). Thus pre-closings of 'We-ell ...', 'O.K. ...' and 'So-oo,' give way to the terminal exchanges of 'Good-bye,' 'OK,' 'Thank you' and 'You're welcome'.

An important factor of closings is that it is ending an occasion:

... it has to do with the organization of conversation as a constituent part of an occasion or interaction. Schegloff and Sacks, 1973: 325.

This organization of conversation is involved with turn-taking (Sacks *et al*, 1974). There were a number of times when the content of interactions did not appear to make sense but residents spoke in turn, taking cues from each other that it was their turn to speak.

Utterances ... do not stand by themselves ... but are constructed and timed to support the close social collaboration of speech turn-taking. Goffman, 1981: 78.

Turn-taking requires social competence and active participation in the interaction order. There were a number of examples in my fieldwork:

Rebecca Jackson and Isobel MacDonald were sitting together. All the time one or other of them was talking. There wasn't always a response but most of the time turn-taking was taking place. Not much of it made sense to me, though recurring themes did occur [from Isobel 'I'm tired' and from Rebecca 'I've nae money'].

At one time Jimmy and I attempted conversation in which neither of us could hear properly, some turn-taking did occur which consisted of us both alternatively saying 'eh'. Most of the time we both pretended we knew what the other was saying in order to save face and smooth the flow of interaction.

'Saving face' suggests strategic collusion and co-operation between those interacting such as Goffman (1970: 10) and Lofland (Lofland L, 1978: 44) suggest occur in interactions.

There were other times when I witnessed this turn-taking between residents, where much of the content did not make sense. On one occasion, Alice Taylor's brother had come to visit her and left the lounge for a while. In his absence Isobel MacDonald sat alongside Alice and the two started chatting. Alice was asking how the family were, and Isobel was replying as if she had family, which she did not. However, by taking the role of someone with a family, Isobel was able to maintain the flow of interaction, working collaboratively with Alice. Isobel also consciously did this to support Alice, as afterwards she confided to me that Alice must have thought that she was somebody else, as she herself did not have children.

At other times there were two totally different conversations taking place in turn. Isobel and another resident engaged in this a number of times, each taking turns at the appropriate cues but each talking about different topics.

Turn-taking in conversation shows a high level of organization and co-ordination between participants. It is not pre-set before a conversation occurs but develops and adjusts to context and situation. Speakers pass between each other and 'overwhelmingly one party talks at a time' (Sacks *et al*, 1974: 700). People typically take turns in 'focused interaction' to maintain focus on a single issue (Goffman, 1963: 24). When it is time for the speaker to change this is indicated by a social cue, and allocation of the turn is made by the speaker or by self-selection, but 'all turn-transfer is coordinated around transition-relevance places' (Sacks *et al*, 1974: 706). In this way, inappropriate interruption is avoided and little space is placed between one speaker and the next. As Sacks *et al* conclude:

Turn-taking organization at least partially controls the understanding of utterances. ... the basis furnished by the turn-taking system for listening, just discussed, may be amplified in the following respect. A participant potentially willing to speak if selected to do so will need to listen to any utterance to find if he is being selected by it to speak next. Sacks *et al*, 1974: 728.

This all suggests understanding, social competence and active participation. That residents in the study engaged in these practices is strong evidence of their social competence, active participation and interactional voice. It is also indicative of having retained social skills, even when some language impairment may have occurred.

Ritual courtesy

Social skills were demonstrated in interactions with me involving welcoming and saying farewell. Additionally, other social graces were displayed to me

during my visits. The most notable resident to do this was Isobel MacDonald, who was also extremely sociable and able to maintain interaction with me beyond the length of a 90-minute audio cassette. In one such taped interview, she checked that I had somewhere to sit, offered me tea and biscuits, invited me to come and stay with her at her holiday home [four times] and also asked:

IM: What's your full name, I want to introduce you.

[Interview, Isobel MacDonald].

This demonstrates that lifelong skills of entertaining have not changed. Sadly, other skills that Isobel had, such as playing the piano, negotiating her way around her surroundings and living independently have now gone.

Similarly, Dorothy McIntosh, who often seems almost totally consumed by her dementia, having lost a great deal of language, has still retained hospitable skills. I went over to her at tea time because she had fallen asleep with her cup in her hands, she said 'It's very good you know' and offered me some.

On another occasion:

Dorothy McIntosh was sleepy but responded well to (VRJ3) Rebecca Jackson's daughter, when she offered her a chocolate. She showed all the surprised and grateful social graces that the occasion demanded.

There could also be a sense of appropriate times for hospitality to be offered:

[RJ and IM are each handed a cup of tea and both say thanks to the care assistant]

IM: You getting it? [to me]

GM: No, I don't want any Isobel, thank you.

IM: I thought she was in something, to give it to you when you were talking to us.

[Interview, Isobel MacDonald and Rebecca Jackson]

Tea drinking seems to be a focal time for sociability and have significance beyond the refreshment offered. It was often used as a means of calming residents, as a distraction from confusion and a welcome opportunity to engage in an everyday activity with others:

Rebecca Jackson slept until about 11.15 am. She woke up happy and grateful for a cup of tea. 'I'm always ready for a cup of tea' she said, 'Yes' I said, 'and a blether'. She laughed and said 'Yes tea and a blether'. She drank her tea and hurried off on a mission.

This association of having idle conversation with tea, although suggested by me, was one that resonated with residents. They constantly wanted others to share with them in tea drinking, perhaps partly because it was something they could offer to others, and partly because of the chat and gossip that accompanied it.

Not only is gossiping, chatting and scandal-mongering a sociable engagement but it also acts as a means of social control. Gossip unites those engaged in it and excludes those not participating. Insiders are gossiped about to other insiders but not with outsiders. It thus becomes a defining feature of 'us' and 'them' (Gluckman, 1963) and will be discussed further in the next chapter.

Saving face

Residents in this study are active participants in interaction, have retained social skills and are able to give and detect social cues. Some loss of

language and understanding has occurred with all residents, the amount varies between individuals. Of great interest to me, despite this loss of content in some interactions, is that meaning is obviously gained from the form of interactions. Participants also engaged in compensatory practices to disguise deficits that might occur in the interactions, to save face and to be polite to others:

Alice Taylor and Rebecca Jackson had a fairly amiable exchange but throughout Rebecca made faces at me and nodded towards Alice suggesting that she was strange. When Rebecca left, Alice said that she was 'a strange person'. Both had been putting on a pretence [of sorts] of polite conversation, yet each wanted to confide to me that they thought the other strange! Was this a way of defining the self as fine by defining the other conversee as 'other' [and strange]? It was certainly a way of remaining polite in the frontstage performance between residents, whilst confiding backstage to me.

It can be difficult to always maintain this politeness to others when there are so few opportunities for privacy. For instance, Susan Stirling one morning upon first coming into the lounge of Lavender Wing responded very quickly to questioning from Isobel MacDonald. She smiled and tolerated others in the lounge for a while before closing her eyes and feigning sleep. This was a means of detachment and creating 'defensible space' (Willcocks *et al*, 1998). It was also a coping strategy and a means of resistance to engagement in interaction and a relationship.

There may have been a certain amount of saving face occurring in turn-taking rituals where the content did not make sense, but another example of retained social skills through ritual could be seen in those to whom religion was important. Betty MacRobert frequently said that she could not remember things, and when she was introduced to a new resident said she

did not know what to say. Her language did not seem to be restricted, but her memory was. Yet when the priest visited her the rituals of religion seemed to overcome this:

Betty was taken through to the dining room and religious murmuring ensued above the clanking of the tea trolley [in both the priest's and Betty MacRobert's voices]. She obviously remembered this ritual. When she returned to the lounge she was humbly grateful to the priest and very pleased about it all.

Religion was also important to Rebecca Jackson and she sometimes worried about how she would get to Mass. During interactions Rebecca was inclined to forget individual words yet when the priest visited her she too remembered every word of the ritual she went through with him. After this she was also very calm as if reflecting on the ceremony.

Role play

Ritual then appears to be retained in a similar way to other social skills by these residents. Another aspect of interactions is that of role play. Roles played by residents in the study varied and could be considered crucial in self definition, in coping with living in a nursing home and in awareness of the dementia condition. One role could be that of the sick person, as with Alice:

Alice Taylor had a sore leg today and kept making a show of walking heroically around the lounge 'to exercise it' and then sitting and swinging her leg.

Alice Taylor often sought attention and reassurance from others and having a physical ailment gave an opportunity to seek this. She also liked to be

seen as being very co-operative to staff. So whilst she might disguise the dropping of some of her meal on to the floor in the dining room by kicking it under the chair of another resident, she would, if instructed, take her exercise because it was good for her. Role play also had the function of compensating for memory impairments for Alice. She talked of the 'old folk' and the help they needed, defining herself as not old by this categorization. 'Of course', she confided 'there aren't enough staff to deal with all the old folk, there's only two. It makes you think we'll get old one day' she said, and then continued to say that she was 100 years old. On another occasion, Alice complained that all Isobel did was 'blether' then started making a lot of fuss, slipping into a role in which she needed help to put her face powder on. This early morning making up the face was, for Alice, a ritual that she had to go through. Alice had a clear sense of some roles that should be played and used them as a means of defining herself. She even had a sense of what my role should be:

When Rebecca Jackson came in Alice Taylor told me to go and look after her. As Rebecca hesitated Alice said to her 'Go and sit with her then and have a blether'... perhaps it was her way of saying 'I'm not a poor old dear, others are worse than me'.

Perhaps one of the most notable examples of role play occurring was one evening when I was left alone in the lounge of Lavender Wing, all the other residents were either in bed or in the process of being put to bed:

This was when Susan Stirling started behaving in a way I had not seen before. I, as usual, collected stray tea cups and put them on the trolley. I didn't realise, but this must have really annoyed Susan because she then started clearing up. She collected the ashtrays and washed them up, and then she got an apron from the dining room and used it to 'dust' every surface, in the dining room and lounge. She dusted the chairs and settees, she rearranged the stools, she tidied the tables. Every now and again she would sit, and sigh or stand, sigh and hold her back. She did not want to

converse with me and even started dusting the chair I was sitting in, only feeling slightly embarrassed when I said I would move out of her way. It was as if she was on autopilot, she had to do it and nothing would stop her. Whilst she was collecting things up she even disappeared into Jane Gilbert's room [where presumably Jane was sleeping] and emerged with a cup. When she seemed finished, we sat in silence, just the two of us, with all the blinds closed and only the tick of the clock to occupy us. After quite a while she left.

This role only occurred when everyone but myself had gone. There were no staff or residents present to witness this. I do not know whether Susan believed this to be her job, whether she was taking the role of care assistant, or whether it fulfilled a need to be active before retiring for the night. On one other occasion I witnessed what may be a clue to this role as a means of defining the self in relation to others:

Susan Stirling was in and out quite a bit. I'm conscious that she needs her own space so was surprised at what I witnessed today. She was chatty and responsive when she came back from the chiropodist. After tea she got into a little social situation. (CA21) was sitting in the chair that Susan likes to sit in and offered to give it up when Susan came in. Susan declined and sat on the stool alongside (CA21). Shortly after this (CA27) came back from her break and sat on the sofa alongside them. Soon (Annie) came along and (CA27) invited her to sit alongside her (between CA27 and Susan), which she did. (CA27) held (Annie's) hand as she sat down and said that her hands were cold. Susan then reached out and touched (Annie's) other hand and said yes, they were cold. (CA21) then reached out and felt Susan's hands. Susan was delighted. It was the sort of thing that I would have thought would have been a real invasion of her space. I was not really surprised at her allowing contact with a care assistant but it was this contact with another resident that surprised me. It was almost maternal, her in the company of care assistants taking on this role herself. This honorary care assistant role does seem to occur a few times. I remember Alice Taylor behaving similarly to Jane Gilbert. It also seems to be a way of distancing the self from dementia and saying look I'm really not as bad as this person I'm caring for'.

Key points

The form of interaction is primarily concerned with ritual and the study of this showed research participants as socially competent and having retained many social skills. Participants detected social cues, engaged in

openings, closings and turn-taking in interactions, demonstrated ritual courtesy and were involved in role play. Effective coping strategies were employed to 'save face' and ensure smooth execution of interactions, this was particularly apparent in turn-taking episodes.

Role play for research participants had a particular significance for self definition, the 'honorary care assistant' role being a popular choice. This had the effect of defining the self as an insider, and excluding others as outsiders.

Conclusion

In this chapter on interaction I have talked about the opportunities that occur for interaction for people living in a nursing home environment who may be experiencing communication difficulties. I have examined what interaction occurs looking at whom residents interact with, what they talk about and the form of their interactions.

The content and form of interactions used by residents in this study serve to illustrate that, despite some language and memory difficulties for individuals, they are still active participants in the interaction process. Social skills are retained, social cues read and a certain amount of role play takes place. Individuals were also able to engage in strategic interaction to compensate for deficits in vocabulary and mistakes in interaction, thus distancing themselves from and disguising problems occurring as a result of the dementia condition. Far from this being a form of deception, it could

be more equated with maintaining the social competence in which we all partake in our everyday interactions.

Whilst most frequently the interactional self shares and engages in frontstage exchanges with significant others, interaction can be broader. The emotional self has been seen to engage in interaction as a means of negotiation and this may be intimate and backstage. The boundary defining self, the subject of the next chapter, may be emotional and interactional, backstage and frontstage. However, the boundary defining self is most often the generalized self concerned with classification and engagement with a generalized other.

Chapter 9: Boundaries

Two aspects of the active social self have been discussed: the first was involved in emotions; and the second involved in interactions. The third aspect to be considered categorizes and creates boundaries. It is the generalized self relating to the generalized other, which is, most often in this study, everyone in Lavender Wing lounge.

As Douglas (1994) has described, systems of classification create categories in social life, although some entities defy clear classification and sit on the separating boundaries. These boundaries represent a threat to social order and are potentially polluting and also potentially sacred.

This chapter is about boundaries relevant to the study. It incorporates boundaries at differing levels: from those of the self and others to the structural boundaries of Deer View Grange and the surrounding community, that I shall call Fairhame. It explores what categorization takes place by residents and of residents in the study, and the constraints put upon them by institutional boundaries. The value in this discussion is that it reveals as much about those defining them as about the boundaries that are defined. When boundaries are most clearly defined there are more opportunities for anomalies in this classification (Douglas, 1994). Thus, when participants in this study separate 'us' from 'them' there is potential for errors, which may require adjustments to be made. When institutions

are involved in categorization, a rule system is developed to maintain control of the boundaries (Douglas, 1986).

In this chapter, I am concerned with the boundaries arising from classification by the institution that is Deer View Grange, and the impact this has on residents. More especially in continuing to examine active social residents, I am concerned with how they classify and create boundaries between the self and others, frontstage and backstage, and inside and outside as well as with the resulting situational domains.

Part of institutional classification is governed and controlled by rules, which in Deer View Grange residents may or may not have agreed to. Residents may break these rules and they may also resist them. Further than this, residents resist the situation in which they find themselves. This is strategic and a means of coping with everyday life. It demonstrates social competence, active participation and individual voices seeking to be heard.

People with dementia could be considered to be in a transitional state and therefore liminal. This, like the culture of nursing homes, assumes passive obedience and what has been likened to social death. However, this view may not be supported for socially competent, active participants who have shown resistance to everyday life.

Firstly it is worth noting some points on the bounding of people who have dementia within a nursing home. Labelling of people with dementia

presents a community dilemma. Stereotypical images of dementia shown in Chapter 3 produce fear. This fear determines how people with dementia are categorized. Incompetence and dependency only become the reality in particular circumstances. These then become a matter of control such as can occur in an institutional setting. This is the context in which people in this study have been categorized and are living – a nursing home – so it is within this context that physical boundaries are considered.

Physical boundaries

The physical boundaries of Lavender Wing and of Deer View Grange Nursing Home at first appear clearly defined. Lavender Wing is enclosed within the Grange, yet has individual distinguishing features. Dichotomous distinctions exist between inside as opposed to outside, public areas separated from private, and frontstage areas as opposed to backstage. Yet a closer examination reveals some anomalies relating to areas which defy clear classification. These anomalies show that the boundaries may be more symbolic than physical but are potentially disruptive to the social order of life within Lavender Wing.

The structure of Deer View Grange is a building of brick walls, one main entrance at a reception area that is either staffed or locked, and a number of alarmed fire exits. Patio doors of the three wings are kept locked unless staff are able to stay with residents on the patio area outside each lounge. It is in effect a bounded area keeping residents in and monitoring those who traverse the boundaries in and out.

Only part of Lavender Wing is separated by doors, the approach being defined by distinctive wallpaper unique to the wing. This approaching corridor is lined by bedrooms and bathrooms used by the residents of Lavender Wing, each with their own door leading on to the corridor (diagrams of Lavender Wing can be seen in appendices B and C). The lounge and dining area are separated from the corridor by glass doors. This design does not impede the pervasive surveillance by those outside the lounge of those inside, and it does not allow privacy within. The corridor, lounge and dining room are public areas of Lavender Wing, where access is free.

Areas which would be defined as private in our own homes may not be considered as such in nursing homes. Bedrooms, bathrooms and toilets are ambiguous; sometimes being private but frequently having this privacy invaded. Residents often need assistance from staff necessitating the blurring of boundaries that would normally define the private areas. It has been pointed out that:

Given the experience of old people within their own homes, the maintenance of privacy, as defined within our culture, may have an important influence on resident well-being. Willcocks *et al*, 1998: 82.

Willcocks *et al* argue the case for privacy for individuals within residential care based on the need to be alone, or to have a private area to entertain visitors. But, Gubrium points out that this extends to privacy infringement when the toilet or sink is shared or someone else leaves their possessions in bathrooms (Gubrium, 1997: 32).

Privacy as defensible space

Residents resorted to their own methods of maintaining some degree of privacy by possessing and guarding property. This could be seen when Rebecca Jackson and Alice Taylor guarded lounge ornaments from being taken by residents of other wings. Guarding of possessions in this way showed that residents had retained the cultural value of private property. Property protection became a means of defining and separating Lavender Wing from other areas of the Grange.

Another example of physical boundary definition and of claiming a private area could be found in regular seating arrangements in Lavender Wing. As part of my record-keeping on each visit to Deer View Grange I noted resident seating plans for Lavender Wing. Seating in the dining room was determined by staff and remained unaltered. Within Lavender Wing lounge the degree of resident autonomy in selecting a seat was determined by the degree of mobility of each individual. Those needing assistance were often placed in the lounge, whilst more mobile residents were able to select according to the available seats. Three research participants could not move to the lounge without help: Jane Gilbert was always placed alongside the hi-fi unit with a table in front of her to prevent her moving; Myra Bains needed assistance and would be placed in the same seat for several weeks, then moved to another part of the lounge for a successive period; similarly, Dorothy McIntosh, who needed additional seat padding for

comfort, would be taken to one seat for a prolonged succession of several weeks before a change to another area of the lounge. The seating of these two residents suggest that there was a policy decision determined by senior staff and instructed to care staff, concerning where these residents be placed. Betty MacRobert also needed assistance to her seat, but having retained more language than the three immobile residents was given a choice of where to sit. All other residents were able to move into and about the lounge with minimum assistance. This then amounted to six residents who were able to make choices about where they would sit in Lavender Wing lounge. Of these, four definitely always sought the same area of the lounge, with Alice Taylor and Betty MacRobert always wanting the same seat; Alice beside the entrance door opposite the clock and Betty in the corner opposite the entrance. As discussed in Chapter 6, Susan Stirling always liked to sit in the same area of the lounge in a seat on her own, as did Jimmy McLean, though as he visited the lounge less frequently his options were often restricted because seats were already occupied. Rebecca Jackson also spent long periods away from Lavender Wing lounge, with the times when she was present usually amounting to those when she had been brought in exhausted from her relentless walking of the corridor. Though usually on the same side of the lounge, she did not have a regular place. As staff were keen to encourage the friendship between Dorothy McIntosh and Isobel MacDonald, Isobel was usually shown by staff to the seat alongside Dorothy.

The unsettling effect on some residents when they could not occupy their regular positions in Lavender Wing lounge suggested that this was important to them. When I discussed with the Deputy Matron, the regular rearrangement of furniture in the lounge, she cited three reasons why this was done: to make things more homely; to create a sociable pattern which would encourage conversation; and to try and discourage possession of one area and thus reduce arguments. Willcocks *et al* recognise that 'the chair in the lounge may become defensible space' (1998:83). In their study they found that staff preferred less institutional arrangements whilst residents preferred chairs placed against the walls. They say that it:

... has to be acknowledged that this arrangement allows residents to avoid prolonged social interaction and to withdraw to relative anonymity. Willcocks *et al*, 1998: 83.

As they point out, there is no reason why they should wish to 'engage in continuous interaction' with strangers. I believe this was most clearly illustrated when Alice Taylor tolerated a visiting resident, who was in for respite care, for limited periods before asking for a table to be moved between them. This not only reduced the necessity for continuous interaction but also acted as a physical barrier, placing space between them.

Closely linked to the physical definition of private bounded areas, for residents in this study, is also the privacy of their own bodies. My research was confined to the public areas of Lavender Wing and I agreed not to enter bedrooms and bathrooms so as not to invade privacy. The boundaries of private areas, where body work took place, often spilled into

public areas, the lounge, dining room and corridor, making them much less clearly defined. A great deal of this was due to the degree of privacy, respect and dignity that staff considered it appropriate to confer on residents.

Many residents were able to go to the toilet unaided and would do so as they wished. Some residents needed occasional assistance for which they would ask and others always needed assistance. Staff approaches to these individual needs varied. Some staff would periodically, and discreetly, ask residents if they wanted to go to the toilet and offer them assistance. I witnessed other staff taking residents, even able residents, into the toilet without a word of explanation. One example of this occurred with Isobel MacDonald:

(CA7) took IM off to the toilet, not first asking her if she wanted to go, or even telling her, but just saying 'We're going for a walk'. (CA20) also went in. I could hear a huge commotion break out from IM and then the care assistants. When they came out of the toilet IM was very pale and also very angry, so angry she looked ready to hit out at the care assistants [she was shaking her arms at them].

The anger of Isobel whilst occurring in the private toilet was clearly audible in the public area of the lounge of Lavender Wing. What was also clear was that Isobel believed that her own privacy, respect and boundaries had been violated by this insensitivity. Several days later, when I was speaking to Isobel, she told me that it was a terrible thing to feel threatened. She did not refer to this incident, but I believe it was one that she would have considered extremely threatening.

Got to get out

If privacy was hard to maintain residents also often spoke of feeling like prisoners within the bounds of Deer View Grange and of wanting to get out. Many would frequently check whether the patio doors of Lavender Wing were unlocked, and also walked the corridor to the reception area to try to leave here. Of the residents participating in the research all but one of the independently mobile people would try to leave the confines of the building with varying levels of persistence. In addition to trying to slip out of the front door unnoticed, residents sometimes questioned me about how I would be getting home, what time I would be leaving and then asked me to call for them before I left. This was a regular request from Rebecca Jackson and one that I heard her also employ with visitors to other residents.

Whilst this desire to get out of the nursing home building was strong and frequent, some of the accompanying emotions that residents expressed, suggested that the boundaries were more than physical. When Alice Taylor wanted to get out it was usually to be with a member of her family, perhaps her brother whom she believed lived 'just across the road', or her mother. On one day when she had repeatedly tried to leave via the front door, been brought back to Lavender Wing each time, and refused to take her coat off, she said to a care assistant 'I will be all right, won't I?' Rebecca's escape attempts, similarly, were accompanied by upset when she said 'If I don't get out of here I'm gonna die'. For both of these residents getting out of the boundaries of Deer View Grange appeared to

signify liberation from everyday life as it had become with an ageing body, dementia and in a place devoid of choice and privacy.

Need to stay in

Interestingly, in contrast to the struggle to be out, there also appeared to be a certain amount of comfort and security from being within. Noise, distractions and lack of privacy in the lounge area of Lavender Wing presented a certain number of disadvantages when I was conducting tape-recorded interviews with residents. Yet, if I suggested we move outside of this area, where most residents spent the daytime, research participants were not in favour. Alice Taylor would not leave her seat. Isobel MacDonald would suggest a walk, on which we would embark, only for her to turn, return to the lounge and find us seats from which to continue the interview. The familiarity of the lounge surroundings helped people to feel more comfortable in the unfamiliar circumstances of having a conversation taped. It may also have offered a less formal opening than would be created by going to another place specifically to tape these interviews.

Tensions also accompanied outings, which from time to time would involve about six residents being taken out for a few hours at a time. In contrast to the excitement and anticipation experienced by many, Alice Taylor would always express disappointment if left out and Susan Stirling and Jimmy McLean would always protest that they did not want to go. I witnessed

Susan Stirling being physically lifted to go on an outing that she did not wish to go on.

Security of being in, against the longing to be out, was also shown on days when the patio doors of Lavender Wing lounge were unlocked and the doors were open. The same residents who repeatedly checked the doors when they were locked seemed to experience confusion when they were open. On one such warm summer day most residents from Lavender Wing were out on the patio with care staff. The patio doors were open and mobile residents could move freely inside and out. Four separate visits were made by residents from other wings, all of whom frequently tried to get out at other times. Now faced with open doors each one of them, in turn, came and closed the doors, remaining inside themselves and shutting the outside out. This led me to reassess my assumption that when residents checked the locked patio doors they always wanted to get out. For some residents, checking the locked patio doors may have been a means of ensuring that they were locked and provided security within.

Key points

Deer View Grange Nursing Home is defined and separated from the surrounding community by physical boundaries. These also serve to determine the bounds of Lavender Wing within; the specific area in which research took place. Within nursing homes, the standard boundaries which would in other places be designated private, are less clear with public

spilling into private and visa versa. Counter to this residents define private areas within the public areas, such as the lounge, areas whose boundaries are defended with props as barriers and by means of claims to ownership.

The physical bounds of the building denote an enclosure from which residents frequently wish to get out. They also often showed that they wished to stay in the secure environment of Lavender Wing.

These physical boundaries of Deer View Grange create the setting in which my research participants can be found. Not only are some boundaries defined for them, but they are also instrumental in the process of definition themselves. More emphasis will now be placed on residents' definitions in consideration of self and other.

Boundaries of self and other

The self is defined in many ways. Three ways in which I witnessed participants doing this were firstly in relational terms to others (Kuwayama, 1994; Shibutani, 1971), secondly by gaining a mirror image from others (Cooley, 1998) and thirdly by the use of narratives (Harré, 1998; Holstein and Gubrium, 2000) which may be expressed to others or to the self. The boundaries around the self, significant others and the generalized other are not immutable, they change over time and situationally. They tell us about the definer, how they categorize and illustrate how much of an interactional and negotiable process this is.

Self in relation to others

Determination of a self definition in the 'reference other orientation' (Kuwayama, 1994) is achieved by reference to others and the similarities and differences that the definer perceives. Discussing characteristics of others often serves this purpose and also tests the reactions of those engaged in the discussion. Alice Taylor frequently used this method of self definition saying that care assistants are tall in comparison to her being a 'wee midgin'. She also said that she always tried to be considerate to others and then qualified this by saying 'like yourself'. This appeared to be her means of ensuring legitimacy and seeking approval from others. As with other interactions it showed strategic usage and social competence. It also allowed for an adjustment of her self image if this seemed appropriate. She would do this by further self referencing, which often led to recounting familiar stories from her past in which she might become even more helpful to others, or coped admirably with a family and working in a pub.

Looking-glass self

Adjustments to the self image are also made when a mirror image is gained from others. Cooley describes this as an emotional response to how we may imagine another to view and judge us (1998:164). From this 'looking-glass self' an emotional feeling is gained and this becomes incorporated into our self image. When residents received visitors there was often pressure from care staff to project a favourable image to the visitors. This was when the 'looking-glass self' was projected in the most visible way as

prompting was given about what residents had been doing. An example of this was when Betty MacRobert's sister visited. The care staff said:

And Betty, have you told your sister about the visit you had when you went on the boat trip. [and later] Betty have you shown your sister the Birthday card you had from us?

Betty would then brightly repeat the story, or show the card. What is questionable is whether the image presented was one of a well-cared for resident, with interest and a sense of self, or a corporate image as reflected in the brochures selling care to clients' families. In this presentation, there is the potential for the sort of conflict suggested by Hochschild (1983), conflict between the felt image and the 'surface acting'. However, on other occasions, there would be straightforward reassurances that affirmed positive self images to residents. For instance, Alice Taylor was always concerned about her appearance and could frequently be seen looking in her handbag for a mirror. She was also very pleased to be told that she looked good and that she was wearing a nice shade of lipstick.

Applying make-up can be seen as putting on a mask to present an image and signify a role to others. For Alice, it provided confidence. This may have appeared very superficial, yet because of the value Alice put on her appearance, I believe wearing make-up affirmed a positive self image for her and importantly that she was held in positive regard by another.

In the nursing home environment as with Stevens' (1997) volunteers who became polluted by contact with marginalized migrant day labourers, and Luske's (1990) psychiatric workers who constructed psychoses for

themselves, there is the potential for care assistants to gain an image by association with people with dementia. They can become categorized as the same as those they care for. In Stevens' (1997) study, the volunteers who worked with marginalized people also became marginalized; and in Luske's (1990) study, psychiatric staff recognised psychoses in themselves. If, as in both of these studies, it is a negative image it will, in turn, impact on the image and any positive self-regard reflected back to residents. This could be seen if staff were unhappy about management decisions or working conditions. At these times, not only did staff regard for residents diminish, but the image projected back to staff became less positive. I saw this happen one day as staff huddled together, discussing changes to working hours and Isobel MacDonald wanted help to find something. She was totally ignored – perhaps the worst rebuff to positive self image an individual can receive, and one likely to lead to a deviant career (Goffman, 1991). Commenting on how bad the service was, Isobel also reflected her dissatisfaction back to staff. In this way images of self are reflected back and forth, entwined with those of the institution and confirming the fact that institutions 'virtually think' (Douglas, 1986).

Construction of self through narrative

In addition to gaining a sense of self from others in these ways, self identity is rehearsed, reinforced and reinterpreted through the narration of the story of self. When people have a lifetime of experiences behind them this is commonly done through the telling of life stories (Harré, 1998; Holstein and

Gubrium, 2000). Even when the memories of recent events may falter with dementia, these residents were often able to recount details of events long past. Through their telling they remained a part of the present and an important element of self identity. With each retelling they reinforced and reconstructed this identity in the context of people's current circumstances. These accounts tell who the person is today by consistent construction of the past (Strauss, 1997).

For research participants, narrating their life story gave an opportunity to present a particular history of their past. An argument made for disengagement in later life, a deliberate withdrawal from social life, suggests that some roles have been lost by the discontinuation of work (Cumming and Henry, 1961). Narrative presents an opportunity to replace these lost roles and carve out an identity of who they are now by saying who they had been, what they had experienced and what they had done during their lives. This is important for defining the boundaries around the self as a person distinct from anyone else.

Boundaries are potentially most dangerous at times of change. Residents participating in this study had undergone many changes throughout their lives. Most recently, and common to all residents, these changes had related to ageing, the onset of dementia and the move to residential care. With each change an adjustment period will have taken place when redefinition of the self will have occurred. In much the same way as marriage redefines personal biographies in the context of the changed

circumstance of the marriage (Berger and Kellner, 1972), the self is (re)constructed in the context of ageing, dementia and changed living circumstances. Accounts are transformed to explain these changes and passages of status (Strauss, 1997).

In Isobel MacDonald's transformed accounts people around her were defined as 'Italian' or 'Scots'. Isobel would narrate tales of her life in the forces, a time when she was apparently surrounded by many people, some of whom she knew well and others whom she did not. She recounted that she always got on with the Italians, but did not always understand them, pointing out someone in the room who was 'Italian'. Then she would continue to point out the 'Scots lassies', the ones she 'shared with', got on well with, and understood. One of the residents would spend long periods of the day groaning and calling for her 'daddy'. This often impacted on the mood of Lavender Wing and tended to promote confusion and chaos. On one such occasion, I was interviewing Isobel, who originated from Glasgow, and she asked me 'Where is she from, Edinburgh? I cannae understand her'. The rivalry that exists between Glasgow and Edinburgh and the distinct identity for people from these places, something that Isobel would have been aware of for all of her life, provided an explanation for her incomprehension of this resident.

Drawing on her experiences from the past to make sense of the present shows proficient application of typifications. Isobel defines the situation in this way, demonstrating both social competence and active participation.

Place was part of Isobel's value system, narrated in life stories and accounted for in transformations. At no time was this more apparent than in Isobel's statement (already discussed in chapter 7) 'I don't really want to be classed as just a person as this ... I would rather be classed a different place'.

Another person who narrated stories of his past was Jimmy McLean. Often with bravado, tales were told of his drunken father, a boxer, of work, of hardship and of camaraderie. Jimmy defined himself by what he had done:

I've been all over the place. I've been all over the country, working, round the houses and that, digging, mining ... never on the dole [interview with Jimmy McLean].

This 'never on the dole' was said with pride, a clear defining feature of self identity.

As I have already mentioned, Alice Taylor was very concerned with her appearance and this was also manifested in her narrations of the past. She talked of her hair being long and put into ringlets, and confirmed the importance of having nice-looking hair by telling me of her regular visits to the hairdressers now. Within her accounts she very clearly spoke with voice, a voice of how she imagined others perceived her:

Always wee Alice, to everyone I was Alice. Everyone would come in the Plough, looking for wee Alice, where is she? I want to give her a hug. [Interview with Alice Taylor].

As in this last account, in self definition the other is always involved. Three others are particularly relevant to self definition: significant others, a generalized other and otherness.

Others

Significant others (Mead, 1967: 150), those thought to be closest to the individual and the generalized other (Mead, 1967: 154) that is the collective society or nursing home community, both have influence in the formation of a self image. The significance of differential power relations is also highlighted when those gaining an image of their self are in a vulnerable and dependent position, as is the case in a nursing home environment. Figures of authority may exert power which influences self images. Participants' resistance to influences and rules of this type will be discussed later in this chapter. Here, I concentrate on definition of others.

Within methods of self definition, evidence of regard for others can be observed. Presenting different performances to different individuals suggests awareness of their significance and the means to distinguish significant others. The desire demonstrated by Alice to present the legitimate version of her past suggests awareness of the judgements that may be made by all and the desire to present a positive image to this generalized other.

When someone is defined as 'other' (de Beauvoir, 1988: 16), subordinate and different, it is also a means of defining the self as privileged and superior. This could often be heard from residents in the study and like self definition was sometimes relational:

Of course it helps them having ones like us here, it makes it better for them. It's awful for the old ones [interview, Alice Taylor].

Uh hum. She's sure of herself, always sure of herself. That's the only thing I don't like [interview, Isobel MacDonald].

They always find something to occupy them [Isobel MacDonald].

She's lost eh? She's in a bad state. Shame that. [Interview, Jimmy McLean].

Talking of, and defining, others in this way served the purpose of drawing boundaries and of defining self by differentiation. It demonstrates a clear sense of self and of social competence and active participation in boundary definition. Definition by residents in this way also dispels previous conceptions of loss of self.

Withdrawal

Though many clearly engaged in exchanges with others and had a sense of self and otherness, two residents who often appeared self-absorbed were Jane Gilbert and Myra Bains. Jane often ignored those who approached her, as if they did not exist, and at other times she sought touch. Myra rarely crossed the boundaries to communicate, remaining encased within herself, though when approached, talked to and engaged in eye contact, would respond, thus confirming awareness. It may have been

that these residents did not always want to engage, rather than that they were unaware of self and others. In fact, one resident from another wing, whom I visualised and privately labelled as 'an evangelical woman' evoked this reaction in many residents and myself. She infringed the convention of respecting personal space and approached people directly into their faces. Compromised by immobile chairs, those approached in this way by her were trapped with no escape. It was a very uncomfortable feeling and one that may reflect that felt by Jane and Myra as they tried to withdraw from this environment.

The nursing home environment does offer an alternative explanation for this withdrawal effect that can be observed in some people with dementia (Willcocks *et al*, 1998). 'Identity comes with conduct and conduct occurs in response to a specific social situation' (Berger, 1991:119). As described in Chapter 6, the social situation of the nursing home is ordered by rules, medicalization and surveillance. This both creates dependency and infantilizes residents. The role of residents is expected to be of passive recipients of care and considerable strategy has to be employed to resist this role.

Key points

Discussion of self and others has shown three ways of self definition; self definition in relation to others, by mirror image and through narration. Each way allowed for approval from others and appropriate image adjustment if

this appeared necessary. Being part of the interaction process, self-definition often also determined how others were perceived. These ranged from significant others to a generalized other and also encompassed 'other' others.

It did appear that the most severely impaired residents withdrew at times. This, like the defence of private space, may have been a mechanism to cope with an environment requiring engagement with strangers. There was no evidence to suggest that it denoted a loss of self. It may, in fact, have been a means of resistance.

Categories and boundaries are not fixed or permanent as they adjust to changing situations. This may most clearly be seen in themes running through the chapters on emotions and interaction. They are involved in backstage and frontstage, and inside and out, which determine and are determined by relationships between self and others as will be shown in the next section.

Situational domains

Previous chapters have outlined how residents slip between intimacy and ritual. Participants' usage of frontstage and backstage performances demonstrate active roles in categorization and definition of boundaries, which reinforce previous discussions on social competence and strategic

interaction. This and definition of inside and outside will be discussed in relation to situational domains.

The three situational domains of intimate, ritualistic and anomic defined by Lebra (1982) arise out of the shifting interplay of frontstage, backstage, inside and out. They produce situational boundaries, which permit appropriate behaviour for the situation. The areas most closely pertaining to intimate and ritualistic domains have been shown in the respective chapters on emotions and interaction, though they are not clear-cut or fixed. Inside and back generally produce intimacy; outside and front point to ritual; and the anomic domain occurs when outside and back occur together. With shifting situations actors participating and categorizing in this way demonstrate clear social competence.

Frontstage and backstage

Some of the boundaries between public and private areas within Deer View Grange were ambiguous, but this appeared to depend, to an extent, upon power relations. The separation between frontstage and backstage illustrates this well.

Surveillance within the nursing home meant that staff often displayed a frontstage performance whilst in public areas of Lavender Wing. This consisted of being friendly and helpful to residents and appearing to be busy at all times. The nature of nursing homes determines that some

activities show this more obviously than others, physical caring being more highly regarded than sitting and talking to residents – undervalued but greatly needed emotion work (Gubrium, 1997). However, staff were not on such public view within private areas, and particularly so in the staff rooms, where much more backstage displays were shown. If residents drifted into the staff rooms, to which they might be drawn by the noise of laughter and chatter, they would be dispatched with less ceremony than from other areas. Staff clearly found resident appearances in their designated rest area an intrusion. Away from the main gaze where they were expected to be kind to residents, staff did not respond as they would in front of management, other residents or visitors. In this backstage environment staff constituted insiders and residents were considered outsiders to them.

Residents' opportunities for backstage performances did appear more restricted than for staff. However, the way that they categorized insiders and outsiders, and defined some others as 'other', did illustrate that residents altered their performances according to the situation and audience. In relation to the boundaries of self and others, residents were seen to make these adjustments with ease demonstrating their competence and active participation.

In the last chapter, examples of how residents use frontstage and backstage, usually to maintain social competence, were shown, in relation to feigned understanding and shared confidences. Additionally, residents may feign conformity (Valentine, 1997) or compliance in frontstage

performance, in order not to stand out in group surveillance (Goffman, 1991). The ritual associated with the presentational self constitutes a frontstage performance. Jimmy McLean and I engaged in this when we could not hear each other but continued the conversation as if we could. Residents also frequently staged ritual frontstage performances to project a particular image in the telling of their life stories.

Alice Taylor slipped between frontstage and backstage with the confidence of someone who had determined categorization clearly. Always polite to care staff, Alice gratefully accepted her afternoon tea and biscuit. Later when I collected her cup she had not drunk her tea and when I commented on this she told me, in a whisper, that it had been too cold and milky. This backstage confidence from Alice was almost defiant and verging on breaking the unwritten rules of etiquette within Lavender Wing. Either she considered me to be an insider with whom intimacies could be shared, or it was a revelation to an anonymous outsider.

A clear example of considering me an outsider and wishing to maintain that position occurred with Susan Stirling. She confined her interactions with me to frontstage performances of polite conversations about the weather, as she mostly did with other residents. With care staff she engaged in less formal exchanges accompanied sometimes by holding their hands. She laughed with staff and showed annoyance with residents and myself, particularly if there was a threat of invading her personal space. By these

frontstage and backstage performances Susan indicated whom she wished to associate with and whom she wished to exclude.

For the majority of research participants, backstage confidences and intimacies usually occurred outwith the presence of care staff, who appeared to be considered as outsiders. The position of care staff is ambiguous because of their constant crossing of boundaries, yet their regular presence inside. As with Luske's (1990) boundary crossing psychiatric staff, their position would be one of outsiders within and this status would carry with it the associated danger.

One evening, care staff were backstage, engaged in putting residents to bed and I was in Lavender Wing lounge with Rebecca Jackson and Alice Taylor, both insiders to this wing. Three residents from another wing of Deer View Grange came into the lounge and started picking up ornaments, napkins and the waste paper basket. Rebecca and Alice were totally outraged at these outsiders trying to take their property and together started shouting and physically trying to regain the objects. They put on a backstage performance only possible in the absence of care staff. They also tried to enlist my support for their actions and wanted me to do something about the situation. It illustrated the ambiguity of my own position, that I was privy to the backstage intimacies denied to care staff, showing that I was categorized in different terms from them. I was often unsure how I was regarded and my position certainly changed in time, situations and with varying actors.

Insiders and outsiders

How position changes occurred can be illustrated. Alice moved the boundaries of insiders and outsiders to include me at some times and not at others. It was obvious from the questioning I received from some residents (Betty MacRobert, Jimmy McLean, Alice Taylor and Rebecca Jackson) from time to time, that they considered my position far from clear. However, I was often privy to backstage confidences that I did not witness being shared with others. This may have been because I was considered insider at times in some situations. Other times I was considered as an outsider, this was clear when Rebecca Jackson refused my help and said 'I don't know you'. It has been pointed out that confidences are often disclosed to strangers in the research process, because as outsiders visiting temporarily they present no threat, as was the case with Okely's (1992) traveller gypsies.

Isobel MacDonald and Susan Stirling appeared to find my status clearer. Isobel always accepted me as an insider, confiding her life history and her emotions to me, yet I saw her display polite, frontstage performances to other residents. This was often a means of maintaining social competence and of keeping interactions flowing, as described in the chapter on Interactions. After one such exchange with Rebecca Jackson, Isobel said to me that she had not understood what the conversation had been about,

and that Rebecca was a strange woman; the disclosure of which placed me as an insider to Isobel, and Rebecca as an outsider.

One of the crucial factors in determining insiders from outsiders is shared knowledge (Goffman, 1991). When Susan Stirling and Alice Taylor had been to the television room to watch a film they were united in their shared experience. This was visible by the way they walked along together, both smiling and both eager to respond to friendly questioning. As they came back to the lounge of Lavender Wing I saw them and asked how they had enjoyed the film. They both responded negatively together. In this action they placed themselves as insiders to the experience and me as outsider and excluded.

The practice of defining those showing outward signs of dementia as other was also a strong factor in insider and outsider definition. The process of defining places others as outsiders to us and discloses who constitute insiders. This is a form of social control that works by exclusion. It may be executed through 'gossip and even scandal' to unite and maintain 'morals and values of social groups' (Gluckman, 1963: 308). In this way the social group constructs an image in a similar way to how the self is constructed. This is done in relation to outsiders and by approving the values of insiders. So, talk of others with dementia, whether compassionate or derogatory, excluded them from this constructed group to which the speaker and audience belonged.

Another insider group would be constructed when visitors arrived, shifting the boundaries to 'possess' the visitors and exclude surrounding residents and staff. The resident with a visitor defines the visitor and self as insider and redefines everyone else as outsider. When privacy for entertaining is so difficult to acquire, creating boundaries of this sort may be the only means of creating opportunities for intimate exchanges.

Jimmy McLean, who was mobile, would often take his visitors away from the lounge of Lavender Wing. This presumably gave them the opportunity for some privacy, and in fine weather when they were able to go outside, Jimmy could also have a cigarette. He welcomed any opportunity to get 'away from the women' of Lavender Wing, and presumably did not wish them to share his visitors and accompanying chat.

Others were not as mobile as Jimmy and had to find alternative means of creating boundaries:

At about 11 am Betty MacRobert's husband arrived. Betty was sleeping heavily until then. When she saw (VBMc1) her whole face lit up into a beaming smile. Betty and her husband were moved to a settee together and she clung tightly to his arm. She turned her back to other residents to focus on her husband, beamed broadly the whole time he was there but there was no verbal interaction between them. Betty's husband chuckled throughout his stay.

Betty turning her back to residents served to exclude them and class them as outsiders, whilst the physical contact and clear delight shared between Betty and her visitor defined him as insider and an obvious significant other.

So, whilst boundaries were often drawn to include visitors as insider by exclusion of others, there sometimes appeared to be a collusion to prevent this occurring. This could be seen by the interjections of staff in their attempt to project a favourable image to visitors, and in performing the

roles of hostesses. It was could also sometimes be witnessed when visitors failed to engage in exclusionary practices of 'outsiders':

Alice Taylor's brother visited her. He is a very outgoing gregarious male who stole the limelight of the lounge. Unfortunately, for Alice it was the Care Assistants he chatted to for most of the hour he visited [2.30 - 3.30 pm]. He did bring flowers; white chrysanthemums. He brought sad news of a relative who had been into hospital with a 'bad leg', listened briefly to Alice and then chatted to (CA14) until she left, and then generally to the lounge after that. I stayed until after he had gone because I wanted to see how Alice was after this. She proudly told me that her brother had visited and brought flowers. Then that was the end of that, she moved on to trivial chat and observations about others in Lavender Wing lounge.

Similarly:

Rebecca Jackson's daughter and son-in-law visited, sitting with Rebecca who tried to move the seats to make a circle. This was difficult, because it would have meant (VRJ1) having her back to Isobel MacDonald. She was obviously not comfortable with this and enlarged the circle to include Isobel, something which, from the look on her face, did not please Rebecca at all.

It was clear that rules of etiquette and of inclusion of those present impacted more on visitors than on the visited. As Goffman (1963) and Schegloff and Sacks (1973) have pointed out, those in continual contact do not need to formalise their interactions or engage in continual talk. Residents would therefore not be bound by the same rules of interaction, or be bound to formality in the same way as visitors were. This can create an anomic situational domain, arising from the backstage and outsider combination, one in which it is common to disregard strangers.

Older people are often seen as outsiders. Having dementia is also often seen as a stereotypical image of old age. Placing people as separate from the community is a way of defining them as other and subordinate (de

Beauvoir, 1988). 'A social boundary is symbolic ... it is also situational, responding to changes in the relationship between the internal and external systems' (Wallman, 1986: 205). This suggests that the boundary has significance to the communities outside and in.

The Local Community

Deer View Grange is situated very close to an industrialised, though village-like, local community, Fairhame. Being in separate, landscaped grounds, Deer View Grange stands apart from this community in which some residents once lived. Many staff and some visitors also come from Fairhame. From within the Grange residents are insiders and the community beyond consists of outsiders. Residents are within the Nursing Home because their incorporation into the surrounding community was problematic and disruptive to families and neighbourhoods. People who have dementia are seen as at risk if they live alone and needing constant supervision if they live with families. Being labelled with dementia places them as outsiders within the community and therefore potentially dangerous. Placing people with dementia in residential care separates them from the community, but they are still enclosed within it. The ambiguity and risk associated with them remaining in the community, without constant supervision, is removed by placing them within the bounded area of Deer View Grange, which is considered 'the appropriate place' (Blaikie, 1999: 194) for their accommodation. The boundary is

redefined and people with dementia become less dangerous as they are now outsiders.

The relationship between residents now excluded from Fairhame and staff who live there and visitors who come from there is interesting. It presents a contradictory position to that presented above. Between people who have grown up in Fairhame there is a great deal of shared knowledge and meaning. This is the sort of shared meaning that allows quick exchanges, without full explanation, but achieving a high level of comprehension. Residents of Deer View Grange who had lived in Fairhame were often a part of these exchanges. Four participants in the research, Alice Taylor, Rebecca Jackson, Myra Bains and Jimmy McLean had all lived in Fairhame most of their lives. Rebecca and Jimmy had daily visits from local relatives, Alice's family now lived a little further away and visited twice a week and Myra's only family member now lived in the North of Scotland and was only able to visit occasionally. What was more interesting than family visits was the contact with local staff members. The regular, almost constant, contact with maintenance, domestic and care staff from Fairhame allowed for quick exchanges only possible with those sharing local knowledge and meaning. One interview with Rebecca Jackson, when we sat in the corridor of Deer View Grange, was interrupted by several short exchanges:

A)

[long pause, then footsteps go along the corridor]

RJ: Hiya [very cheerily]

Reply: Hiya Rebecca

[pause]

B)

[domestic goes along with trolley]

Domestic: If I've no' got one trolley, I've got another.

RJ: [laughs] Aye.

[someone else goes along corridor]

Hi Rebecca.

RJ: Hi.

C)

[someone goes past] Hiya

RJ: Hiya

[pause whilst footsteps go away]

D)

[Rebecca and I are walking along the corridor when we see a care assistant, Rebecca calls out to her]

RJ: Hello there, where you goin?

Reply: I'm goin up to get some bread for the lunch, is that ok?

RJ: Aye, make sure you do.

E)

[long pause]

Staff nurse approaches: Hiya Rebecca, you all right?

RJ: Aye.

[Someone else going past]

Voice: Having a wee rest Rebecca?

RJ: Hiya. My feet are killing me.

Voice: Your feet are killing you, why haven't you got your slippers on then?

RJ: Mind this big bloke [maintenance man walks past]

Maintenance man: Aye.

[he goes off whistling down the corridor]

RJ: Well

Another voice: Rebecca.

RJ: Hi there.

F)

RJ: I'm late, agin

Maintenance man: [going past] Again, Rebecca.

RJ: [something I don't understand but very lengthy]

[they both laugh]

Many of these were short exchanges and there may appear to be little content in them, but what was significant was that others did not always initiate them and Rebecca's responses were sharp and instant. When this is contrasted with the slow and difficult exchange that was taking place between Rebecca and myself, I feel it does demonstrate a significant relationship between local people.

Someone else who frequently engaged in what could be termed 'banter' with staff from Fairhame was Jimmy McLean. Unfortunately, none of this was taped, but I often witnessed lengthy exchanges between him and one particular care assistant who told me she had known Jimmy all her life. I could understand very little of what they said, but other people were frequently mentioned by name during the course of the conversation. Exchanges were rapid and cheerful. Gubrium (1997) says this is a 'hidden tie' and a way of maintaining networks from outside even when direct contact does not take place. I asked this care assistant about her relationship with Jimmy. She told me that it was special, but that it was also upsetting for her both to see Jimmy 'like this' and, as she said, that he sometimes forgot that he had known her all her life. However, I believe these exchanges would not have been possible unless he had.

Within these exchanges were clear examples of social competence from residents. They also provided an opportunity for inclusion into Fairhame community life as customs and news were brought inside by those traversing the boundary of Deer View Grange on a regular basis. It served

the same purpose of inclusion as already attributed to gossip, by excluding those not from Fairhame. As a form of social control, an institution for those posing risk to the surrounding community must be the ultimate.

Key points

Frontstage and backstage performances and definitions of inside, outside, insiders and outsiders combine to produce fluid situational domains. They account for intimate, ritual and anomic behaviours. My prime interest was in how residents used these, but the use that others made of them also impacted on residents. Frontstage was concerned with presentation within the surveillance culture. From staff, this involved presentation and from residents it consisted of compliance. These were sometimes genuine and at other times feigned. Backstage is shared between intimates in similar circumstances but in the absence or by the exclusion of others.

Others coming in to the Grange as visitors prompted changes in who might be defined as insiders and outsiders. The public nature of the environment prompted exaggerated forms of definition by residents in an attempt to claim some privacy when entertaining visitors.

The local community of Fairhame surrounding Deer View Grange showed an anomalous situation concerning boundary definition. Residents from Fairhame have been excluded by confinement within the Grange, but are

often included in gossip and chat requiring local knowledge. This does serve to exclude those residents not originating from Fairhame.

Conventional accounts on dementia were seen in Chapter 2 to evoke fear emanating from dark images, which are phrased in terms of loss and decline. This identifies dementia as dangerous, not easily defined and therefore on the boundaries 'betwixt and between' categories. People who have dementia, by association, are also defined in these terms and therefore a danger to the social order. Correction to this anomaly takes the form of removal from the community, separation and segregation. Deer View Grange Nursing Home is separated from, yet enclosed within, Fairhame. In this boundary, residents are controlled and their risk and threat removed from Fairhame. In order for this to occur, they are subjected to rules.

Rules and resistance

Rules

In chapter 6 the discussion of the culture of nursing homes showed that a great deal of constraint is put upon residents by surveillance and rules. Justification for operating under a medicalized ethos, when no treatment or cure for dementia is offered, is made by such practices as monitoring bowel movements. Residents are encouraged to take drinks and tablets by being

told 'It's from the doctor'. The discipline requires routine and rules for the smooth and efficient running of the establishment.

One of the most contentious rule sets, designed to allow choice by individuals, relates to the issue of smoking. The residents' charter as laid out in the Nursing Home Information Booklet states: 'Residents have a right to smoke if they wish, choices and risks acknowledged. Those residents who do not smoke have a right to a "smoke free" area'.

There were designated times for smoking, after each meal and the designated area was Lavender Wing lounge. At these times smoking residents would be handed a cigarette and ashtray and a care assistant would light their cigarette for them. Sometimes these smoking residents might be seated next to a non-smoking resident. The windows would be opened for ventilation.

Isobel MacDonald, Dorothy McIntosh and Rebecca Jackson, all non-smokers, often complained of being cold at these times. I never heard any resident being asked if they wished to leave Lavender Wing lounge whilst residents were smoking, although many needed assistance to leave.

As the ruling regarding smoking does not appear to satisfy the right of choice by non-smokers, I should then have to question what purpose it serves other than to control and to appear to offer choice to smokers. The abuse of power by care assistants when making smoking residents wait for

their cigarettes, or in the case of Jimmy McLean telling him that he is not allowed a cigarette because he has not eaten, also calls into question whether smokers are allowed choice by the ruling. How they may gain a right of choice or find a coping mechanism for lack of choice is through resistance to the rules.

Resistance

The following excerpt from the poem *Warning* by Jenny Joseph (1996) sums up what resistance to old age may be like:

When I am an old woman I shall wear purple
With a red hat which doesn't go, and doesn't suit me,
And I shall spend my pension on brandy and summer gloves
And satin sandals, and say we've no money for butter.
I shall sit down on the pavement when I'm tired
And gobble up samples in shops and press alarm bells
And run my stick along the public railings
And make up for the sobriety of my youth.
I shall go out in my slippers in the rain
And pick the flowers in other people's gardens
And learn to spit.

That there should be this active resistance to old age as suggested in the *Warning*, is indicative of the expectations of others, that older people will conform to stereotypical images and that there are restrictions placed upon them by others. I am sure that there were many times when residents of Deer View Grange wanted to spit. Their retained social skills prevented them from doing so.

In Chapter 2 it could be seen that resistance to entering a dependency culture, be that residential care or living with children, was strong amongst older people. Many were prepared to make themselves homeless (Crane, 1999) or live in poverty slum hotels (Stephens, 1976) rather than relinquish rights of choice. Participants in this study had entered a care environment, yet this does not mean they did not offer resistance. This took the form of resistance to the environment and 'escape attempts' (Cohen and Taylor, 1998) from everyday life.

There were many ways that residents actively showed resistance to the rules, boundaries and environment in which they now lived. Constant attempts to get out of the building, 'escape attempts', are an example of this. The reaction of staying in when the patio doors were open was also an indication that these escape attempts were as much a means of testing the boundaries as of wanting to be out.

Returning to the issue of smoking, it is clear that non-smokers are disadvantaged by the rules that allow smoking in Lavender Wing at designated times. They also appear powerless to do more than complain of the cold. Smokers are perhaps in a stronger position to resist them. After every meal Betty MacRobert would ask for a cigarette and be told she had to wait, usually because care assistants were too busy just at this time. It seemed that the more Betty asked the longer she had to wait. Jimmy McLean kept his own cigarettes, brought to him by his sister, but had to be given a light by staff. He always smoked two cigarettes when given a light,

lighting the second from the first. Similarly to Betty, he was made to wait for a light if he asked for one. The only other participant in the research who smoked was Susan Stirling. She never asked for a cigarette, would sometimes be absent from Lavender Wing lounge when they were given out and would then look very upset when she returned to the lounge. She would then keep looking towards the care assistants as if willing them to offer a cigarette or trying to become brave enough to ask for one. Characteristically, it appeared that Susan would never do anything to upset those she perceived as in authority and always seemed to do everything expected of her.

Erikson (1961) points out that deviance serves the purpose of testing moral boundaries. Neither Betty nor Jimmy would be considered as particularly compliant residents in the way that Susan would. Surveillance would easily show them as standing out from the group (Goffman, 1991). In their repeated asking for cigarettes and lights, probably already knowing that this would delay their issue, they were deviating from the rules and able to test the boundaries regarding smoking. On only one occasion I witnessed their requests granted without delay or question and this was when the Grange was undergoing inspection by the Health Board. On this occasion the boundary was moved, the rule of control was relaxed. This was a strategically presentational frontstage performance. It was only temporary and once the inspection was complete the rule of control was again enforced.

Another example of resistance arose with Rebecca Jackson. Though care staff tried to coax her, on this particular day Rebecca did not want to go to the hairdresser and refused outright. The care assistants were annoyed at the energy they were investing in trying to persuade her and at the possible disruption to the established 'hairdresser day routine'. Rebecca's tactic was one that I saw used by many residents to avoid a situation or further interaction, she feigned sleep. Sitting in Lavender Wing lounge with her eyes closed, Rebecca continued to talk to me throughout. After a period of time the care staff became busy with bed-making outside the lounge and Rebecca immediately took the opportunity to get up and leave the lounge undetected. She stayed away from Lavender Wing lounge for the remainder of my visit.

In addition to Betty showing signs of testing the boundaries on the issue of smoking, I also felt that she deliberately behaved in a defiant way at times, breaking the rules of etiquette. She seemed to get great pleasure from the disgust of Alice Taylor when she dunked her biscuit in her tea and placed it in her mouth whole. I saw her several times wait to ensure that Alice was watching before she engaged in this.

There was a certain amount of admiration from other residents for acts of resistance, consistent with Bethal's (1992) findings in his study. This example from my fieldnotes again involves Betty MacRobert:

When BMc was brought through to the lounge after breakfast she was seated on the settee in the middle of the room. She immediately curled her

legs up and lay down. She looked defiant as she did it, and was told to sit up as soon as a care assistant saw her. With an impish look upon her face she sat up and (Julie), a resident from another wing of Deer View Grange, sat next to her. Soon (Julie) got up again and BMc again lay down. JMc laughed and SS said, with a smile on her face, 'I knew that would happen'. BMc appeared to gain admiration for her deviance from other residents. Once again she sat up when scolded by the care assistant and immediately she requested a cigarette. BMc was made to wait a while for her cigarette, but it was almost like she was using her compliance of sitting up, as a bargaining point to get what she wanted, a cigarette.

This deviance and bargaining pattern was not an isolated incident. It suggested competent use of strategic resistance to the environment and rules.

Examples of resistance to the environment could also be seen. Often residents would sleep because there appeared to be nothing else to do. But sleeping was also associated with the choice of privacy and of distancing from the group. Susan Stirling would often feign sleep to avoid talking to neighbours and often talked to herself in preference to others. She clearly did not wish to associate with other residents, but waved her hand to people walking their dogs outside. This act of feigning sleep, like the feigned compliance of prisoners (Fox, 2001) and conformity (Valentine, 1997) is a strategy and means of resistance. There would be no reason for Susan to wish to engage in 'prolonged social interaction' rather than 'withdraw to relative autonomy' (Willcocks et al, 1998: 83).

Alice Taylor also registered her resistance to the environment when she longed for home. On more than one occasion, when she expressed this longing, she went and got her coat and sat with it on in the lounge of

Lavender Wing. She thus demonstrated in a very tangible way that she was ready to go home and did not wish to remain there.

In many of these forms of resistance such as longing for home and requesting cigarettes there was a 'contagion', which like certain emotions, particularly anxiety, were seen to spread amongst residents. Admiration for acts of resistance also seemed to spread in this way. I only witnessed collective action by residents when staff were away from Lavender Wing lounge. An example of this was when Rebecca and Alice united against residents from other wings to protect the property of Lavender Wing.

The next example also suggests that the expectation of deviant behaviour accompanying dementia could be incorporated into this strategy:

RJ was very sleepy until towards the end of my visit when she went through to the dining room and started getting cups out of the cupboard and putting them on the dining tables. It seemed very logical laying the tables, but when (CA17) came and found her she stopped her from doing it. RJ then started to wander around swearing under her breath. When she walked past me she gave me a wink. It was very clearly a wink and a smile.

This act of defiance was Rebecca's way of dealing with the imbalance of power, infantilization and humiliation of being stopped from doing something useful. I believe she was also testing the boundaries and distancing herself from the situation (Goffman, 1972). Another example of this occurred with Jane Gilbert:

The doctor came in to see JG. When he saw her he approached her with (SN1) and said 'Hello'. He then proceeded to examine JG without telling her what he was doing, she immediately kicked the doctor.

Whether this was strategic usage of stereotypical expectations of her behaviour or not is difficult to determine. Whether it was strategic or not Jane clearly indicated to the doctor that he had invaded the boundary surrounding her and that it was indeed dangerous to do so.

If resistance acts as a coping strategy for living in a constrained environment, deviation from the rules can place those who deviate as outsiders:

Social groups create deviance by making the rules whose infraction constitutes deviance, and by applying those rules to particular people and labeling them as outsiders. Becker, 1991: 9.

However, resistance appears to be so prevalent that it may be those who do not deviate from rules who are deviant. As Valentine points out:

Nonconforming others are . . . already included in the identification of conforming selves. Valentine, 1997: 111.

This is because the potential for transgression is a part of conformist groups, boundary defining and provides a means of relational self definition, through difference rather than sameness. However, conformity, or the apparent presentation that individuals conform, can be strategic and when shielding deviation is an effective means of resistance. Examples of this have been shown, though not explicitly described in these terms, as when Rebecca Jackson gave the impression of sleeping to order and when Susan Stirling complied with staff wishes.

Another perspective on this argument for resistance is concerned with labelling and the career of dementia. Research participants were labelled

with dementia by virtue of the fact that they lived in a dementia specific nursing home. If the images that they are presented with are that people with dementia behave in a particular way then they may adopt this behaviour and embark on the trajectory of a career with dementia (Goffman, 1991). If residents do follow the career of dementia in this way, it certainly has a bearing on their construction of self and identity. These would be adjusted to take account of dementia. However, if they played the role of having dementia, as seemed to be the case with Rebecca, it becomes one role among many that will be performed.

Key points

The nursing home environment is bound by rules which, together with social etiquette, the environment and dementia, constrained and restricted what residents could do. Although they had not been able to resist entering this culture, they did employ many other forms of resistance as coping mechanisms for everyday life.

By deviance and rule-breaking boundaries were tested. This took the forms of apparent conformity, distancing and defiance, all of which were strategic. Definition of self and others, by highlighting what was the same and what was different, was also a part of this.

It is apparent that engaging in resistance required an understanding of, and engagement in classification, active participation and a high degree of

social competence. Through the exercise of these voice was heard. This could be a major function of resistance.

Liminality of people with dementia

As I got to know the nine participants in this study, there was no doubt to me that they were all individuals with varying preferences, needs and biographies. It seemed that residents were able to employ effective means of resistance to their circumstances and to dementia, both of which placed obstacles in the way of negotiating everyday life. It is for this reason that I should like to present an argument for the liminality of people in my study, who incidentally also have dementia.

Liminality is a transitional state, on the boundaries and defying classification. Whilst most boundaries are potentially dangerous, liminality is more often regarded as sacred. Liminal entities in many cultures are those about to take part in an initiation ceremony or rite of passage. During a liminal phase initiates are expected to behave passively, and obey those who are teaching them new social rules in line with changing status (Turner, 1995: 95). In Japanese culture, for example, children and old people are thought to be liminal because they are on the threshold of life and death (Iijama, 1987).

It has been argued that people with dementia suffer 'social death' (Sweeting and Gilhooly, 1997). Participants' exclusion from Fairhame

community would reinforce this argument. This social death would place Deer View Residents as 'betwixt and between' (Turner, 1995: 95), on the boundary between life and death.

Older people are often preoccupied with death, their own and those of people they know, and examples of participants discussing this have already been highlighted in the last chapter. Whilst our society may be uncomfortable in talking of death, to do so may be older people's way of preparing for it. In addition to this, people with dementia may at times focus on their past rather than the present. They may believe they are with others who are no longer alive.

From some of the profound statements that have been made to me by participants in my study, I believe many residents show highly developed social competence, active participation and proficient usage of metaphor to communicate with people who do not have dementia. This contradicts the passive relinquishing of control that both liminal people and nursing home residents are thought to share (Sweeting and Gilhooly, 1997). The degree of social competence demonstrated by residents was not matched by that of many with whom they interacted, who made the assumptions that residents would comply with the passive stereotypes.

Conclusion

This examination of categorization, boundaries and boundary testing reveals much about everyday life for people with dementia living in Deer View Grange Nursing Home. Research participants were both subject to boundaries imposed upon them by others and active in categorization and boundary creation themselves.

Whilst the physical boundaries of the building appear most immutable, their symbolic significance is revealed in the emotions of being bounded within, and risk avoidance for the benefit of those without. The forces of the nursing home and surrounding community group individuals within.

Social boundaries defining the self, others, who should be included and who excluded, are variable and subject to constant reassessment by individuals in everyday life. They are key in self definition and maintaining or restructuring personal biographies.

Residents living in a dementia specific nursing home are subjected to rules, stereotyping and labelling. This act of labelling places them as deviants and outsiders. However, against these adversities, research participants showed great resilience and resistance, and tested the boundaries. This required active participation and social competence. It also demonstrated that they should be considered in positive rather than in derogatory deviant terms.

It has been suggested that older people with dementia may have experienced social death. However, the degree of social competence demonstrated by research participants, together with active participation in defining boundaries, contradicts this. In this research residents did not conform to stereotypical images of nursing home residents as passive recipients of care. They did not relinquish control as initiates in rites of passage do, but instead actively resisted.

This has been the third sphere of the active social self to be discussed. It has added the generalized self to the emotional and interactional selves. Through engaging with the generalized other, classification and boundary definition was undertaken by and of residents. This also involved elements of intimate and shared spheres of relationships as backstage and frontstage, self and significant others, inside and outside situations occurred. Much of the competence of residents was demonstrated by the way that they could change between these within the same exchanges. They also competently situated themselves and their sense of selves in relative terms to others. This involved active participation and through this, particularly in terms of offering resistance, residents were shown to have voices.

Chapter 10: Conclusion

This ethnography has been about people. At the time of the fieldwork, all resided in a private nursing home. One aim of this study, from the outset, has been to gain the subjective views of people who have dementia. Once I had also met my research informants, I wished to explore the extent to which they might be active social participants. Until this point, the impression I had gained from the literature and popular characterisations was that dementia was a debilitating disease leaving little capacity for communication or active participation. There had also been a body of literature suggesting that people who had dementia underwent a 'loss of self'.

The negative images of dementia, due to the perspectives from which it had been viewed, focused on the disease rather than the person. Following Kitwood (1997) and Post (1995), I aimed to reverse this focus and place the person first. There were two aspects to doing this and they were concerned with who informed the research and the way the collected data was examined.

Domination of the medical model in both care and research had produced a particular perspective, which could not place the person before the disease, and would therefore always frame dementia in negative terms. Conversely, sociology by definition is concerned with studying people in social context and provided the theoretical basis to apply alternative social filters.

Using a social perspective to view this study also required the collection of appropriate data. A key part of gaining this data, I felt, was in the selection of appropriate informants. Health professionals and family carers had informed the majority of dementia studies prior to this one. The resulting data had been their impression of what dementia was like. This had the effect of silencing those with dementia, perceiving them as passive recipients of care and on a passage of linear decline. Yet, there had been calls to give 'voice' to people with dementia and to gain their views. This was the intent of this study.

In placing the person first, my theoretical framework clearly could be any model by which people are usually studied. My interest in relationships thus provided an appropriate cue to this. Micro sociological theories provided an ideal means of studying relationships. To conduct the study in everyday life offered a range of theory to apply to aspects of relationships. With the person with dementia at the centre of these relationships, spheres of understanding emanating out from them could be examined. From a theoretical standpoint I considered the self, significant others and a generalized other, represented in relationships by concentric circles. Analytically these proved to be too fixed and failed to represent fluidity in relationships. Once developed, the emotional self, the interactional self, and the generalized self of the person could be shown as aspects of a social self in everyday life. When examined in these terms, the people with dementia who acted as informants in this research were seen as socially

competent and active participants, who, when given the opportunity, could voice meaning in their social worlds.

Careful selection of methods was one way in which these voices could be heard in the research process. Ethnography allowed time, depth of information and familiarity to be gathered. Reduction of the activity and initiation by the researcher allowed more active participation by research informants. My apparent passivity in the process gave time for initiation of interactions by residents, an opportunity each one of them took regardless of any communication difficulties, by welcoming me on arrival. This passive ethnographic approach was lengthy, time-consuming and at times tedious, but it paid dividends in the resulting data and the chance to get to know each research participant individually. It represented an innovative methodology for researching the subjectivity of dementia.

This study took place in one setting, Lavender Wing of Deer View Grange Nursing Home. The Grange was designed and built for people with dementia, Lavender Wing housing twelve residents, nine of whom were research informants. Being new to both the field of dementia research and to research involving nursing homes, I did not anticipate the impact of this environment on residents. There was a strong disabling effect that was often wrongly attributed to dementia.

This culture was one of surveillance, routine and restriction. Emphasis was on twelve residents being kept as a group for effective and efficient control

by staff. As monitoring was not only of residents, there was also an atmosphere of favourable image projection from all. Thus, care staff most frequently engaged in visible bed and body work, residents were careful to appear to be compliant and presentation to any extending the gaze was given priority over less visible emotional support.

Restrictions for residents consisted of lack of privacy, limited choices and a tendency for staff to infantilize residents. This could be seen in the way power and control were used in exercising rules regarding smoking, and in the way the routine was designed around staff availability. This meant that supper might be served at 4.30pm, bedtime might be 5.30pm, and residents might start to get up at 5am. Nevertheless staff said that Mrs Jackson had turned night into day and that this was common for people with dementia.

There were two major theoretical developments that occurred as I conducted the fieldwork and analysis. Firstly, as links between data and theory developed, three major themes became apparent which related directly to the chapters on emotions, interactions and boundaries. Originally conceptualised as concentric circles emanating from the self which represented relationships with others of varying significance, these themes became much more fluid. The fluidity of the resulting floating amoebae represented the competence with which residents participated socially, engaging with the self in thoughts and memories, with significant

others in interactions and engaging with a generalized other consisting of everyone in Lavender Wing to classify and define.

These three thematic areas were concerned with intimate, shared and generalized relationships. Within each of these spheres residents sometimes engaged in backstage intimacies and shared frontstage presentations. They also defined and were defined by boundaries through classifications. Linking strongly, these three spheres, whilst each dominating primary characteristics of their particular area, do not do so exclusively. This is what allows fluidity in relationships.

The second development and part of these three thematic areas was in my discovery of turn-taking, which I witnessed in fieldwork. This had not been a phenomenon that I had been aware of prior to this and I found the relevant literature subsequently to the fieldwork discovery.

Within the restrictions of the living environment and of having dementia, when studied within a theoretical framework of everyday life, residents used effective coping strategies. They could be seen to express and want to talk about a range of emotions and sought emotional and social support. Emotions were contextual to relationships and part of social life, sometimes involving reference to or awareness of dementia. Relating to others, to the self, to the present and past they showed empathy, compassion, anxieties and upset. In this process, they engaged in what Blumer (1986) termed

'sympathetic introspection' which requires the ability to take the role of the other. I found no evidence of loss of self.

Study of interactions in which residents were involved, revealed compensatory practices and social competence, whether or not communication difficulties were experienced. Interaction was used strategically in order to present favourable images and as a means of negotiating competence and relations with others. It was also ritualistically collaborative, in order to maintain interactional flow, engage in turn-taking, help others save face and help in the conveyance and comprehension of meaning.

Engaging in the definition of boundaries, residents categorized and were similarly defined. They also actively engaged in redefinition in response to how they imagined others perceived them. Social participation in this way required competence, confidence and experience. It demonstrated the ability to adapt to changing situations and situational domains. Intimacy, ritual and anomic responses to inside, outside, frontstage and backstage were performed with ease. As well as being controlled by others, residents participated in the controlling process and defined others as insiders to be included or outsiders to be excluded.

Resistance to the environmental controls and to dementia displayed further competence. By breaking rules, boundaries were tested and classifications redefined. By feigning compliance, resistance could also be offered.

Another coping strategy and a means of gaining some privacy was in withdrawal and in territorial defence of privately defined areas within public rooms. In these ways residents found means to resist restrictions. But, dementia also presented restrictions to residents at times and ways of resisting or coping with these were also apparent. In interactions substitutions would be made when words were lost and the co-operative nature of ritual also often compensated.

In consideration of the liminality of people with dementia there was a striking similarity between people with dementia living in nursing homes and initiates in rites of passage. Both could be defined as on the boundaries and both are expected to be passive, obey instructions and take punishment with stoicism. In the liminal phase, liminal people are silenced and their voices not heard. However, there is a disparity between these expectations and empirical evidence from this study. Research informants demonstrated socially active participation, which dispelled this myth along with similar suggestions that people with dementia experience social death and disengagement.

There are limitations to this study, in part arising from the limited studies of a social nature to date in the field of dementia studies. Allan's (2001) recent research demonstrates that there is still considerable work to be done to improve communication with people who have dementia. For my study, I relied on being able to spend time with a small number of people,

to encourage communication on their own terms. In a larger study, or one requiring rapid data results, this approach would not be possible.

In studying this group of people who had dementia, I had little knowledge of their pasts and biographies before they had dementia and before they lived in a nursing home. This inevitably restricted my interpretation of the situation, as a great deal of contextual information was missing. By studying them in a nursing home, whilst it might be thought of as the 'natural' setting that Blumer (1986) suggests for study of people in the sense that it is where they conduct everyday life, in another sense it is a very unnatural setting. Empirical evidence suggested that it was not where residents chose to be, it had taken them from the familiar settings of their own homes and placed them with other people whom they did not previously know. However, until this study had been conducted, I did not understand its significance. It will guide any future research that I do in this area.

One aspect of this study that I had not anticipated was the impact that living in a nursing home can have on people, in terms of restriction. In many instances, the restrictions of the culture are such that they may disable residents as much or more than dementia does. This discovery contributes to previous investigations of the culture of nursing homes. Residents' responses, particularly those that demonstrated resistance, add understanding to this and provide additional evidence of the nature of the culture. That residents in this study were able to offer resistance to both of

these demonstrated active participation and social competence. However, if I were to start this study again, I would not conduct it in a nursing home. Alternative ways of gaining ethnographic data of this depth would be hard to find, but a comparative study of different living environments could prove useful. The cultural bias of the nursing home was certainly such as to impact pervasively on the everyday lives of residents in this study.

There are contributions that this study can make to our theoretical and methodological understanding, and also to the field of dementia studies. Through gaining the subjective perspective from research participants and in ethnographic method to interpret and describe, voice has been given to nine people with dementia living in Deer View Grange Nursing Home. This adds to our understanding of what it is like to be in these circumstances and provides empirical support for suggestions that more consideration should be given to personhood. By placing the person first, we can learn of dementia from a social and sociological point of view.

Seeking sensitive and ethical methods to explore these circumstances of vulnerable people has highlighted areas of concern for all social research. For instance, the issue of consent to research measures put in place to protect vulnerable people applies to researching any people. Whilst guidelines suggest that negotiation of consent should be continual, the importance in this case is particularly poignant when an informant may forget that they agreed to research previously. It cannot therefore be assumed that consent be a single negotiation.

Sensitivity in data collection methods is also required when dealing with vulnerable people, which highlights the potential imbalance in power relations between researcher and researched. This, like the matter of consent, is one which should be considered to apply to all social research.

On the issue of consent to research, the question of competency has not been resolved or silenced in debate, it has now become a matter of capacity. Beyond the implications for consent, capacity like competency is concerned with all decision-making and choice. Recent research (Allan, 2001) and the first act to be passed by the Scottish Parliament 'The Adults with Incapacity (Scotland) Act 2000' reflect the continuing concerns.

Following Goldsmith's (1996) work on hearing the voice, Allan (2001) worked to improve communication between care staff and people with dementia. She found that when using methods where people with dementia are given 'maximum control' with verbal and non-verbal communication staff expressed surprise at:

"... the levels of insight and responses from clients even though profoundly demented and often said very little" (manager quoted in Allan, 2001: 96).

and she also quotes one staff member:

"It's made me more aware of the fact that memories don't just disappear but are buried quite deep" (staff member quoted in Allan, 2001: 96).

These are encouraging insights, but they do, as Allan points out, require changes in care working practices. These would involve emphasis moving away from what has been described in my work as the visible work of care

staff. Hearing the voice takes time, skill and patience, whether staff are able to engage in these is dependent upon the prevailing cultures in which they work. In short, more resources are required in nursing homes, to enable such improvements in communication with people who have dementia.

The Adults with Incapacity (Scotland) Act 2000, also attempts to involve those with incapacity in decision-making whenever possible, making provision for advocacy and guardianship when not. As implementation is under way (April, 2001 to April, 2002) we have still to witness how effective this will be in enabling decision-making by people with dementia. My concern remains, as it does with competence, one of who decides upon capacity? It is to be hoped that in consideration of capacity, notice will be taken of findings which suggest competence, and participation of people with dementia, until it has been shown that individuals do not have these.

By conducting a sociological study of people not thought to be social, and discovering social competence in those thought to be socially incompetent this study challenges sociological theory. A strong case could be presented for testing and moving the boundaries of social inclusion. In relation to the Adults with Incapacity (Scotland) Act 2000, there could be implications in the way people with dementia are perceived with regard to incapacity and therefore in the implementation of this Act.

The perspective and methods selected in this research have the potential to change the way we think about people with dementia. In this way it adds to our knowledge of the field and may influence future dementia research. Through seeking to find active participants and voice, empirical evidence has supported an image contrasting with one of loss, decline and incompetence. This allows us to see beyond dementia and to hear what the person has to say. Lessons from disability studies if heeded should enable us to hear all voices and not just those that say what we want.

There are also other areas of research which have arisen during the course of this study that, I feel, are worthy of further investigation. One of these is the study of transitions with regard to dementia. At least two major transitions had occurred for all the residents involved in this study: from being a person without dementia to becoming a person with dementia, and from living at home to living in a home. Other major transitions had affected many, such as bereavement, illness and role changes. Each of these transitions impact upon people and may reduce the amount of social support and friendship available. The point of transition is that of potential pollution and danger, as for initiates in rites of passage, and the amount of support available will in part determine the outcome. This is an area worthy of further investigation.

The second area that I should like to research further is in part related to the last point about transitions and social support. It was clear from the literature (particularly, Crane, 1999, and Stephens, 1976) that there is a

great deal of resistance to entering a dependency situation, whether this is residential or nursing care, or living with an adult child. That resistance also occurred within the Grange suggested that many did not want to be there. I should like to explore whether, in order to resist becoming dependent, people with dementia become homeless, and if so the extent of this.

There are implications that can be drawn from this study for relationships of people with dementia. Within nursing homes there may be implications for care workers. They were never the subject of this study, but the relationships that care workers have with residents in care clearly impacted upon people with dementia. As a means of survival and perhaps escape attempts of their own, care assistants in this study often appeared to ignore requests for social support from people with dementia. They may be in internal conflict due to their own unmet emotions and in this surveillance culture take their lead from senior staff. However, if they consider residents as socially competent and active participants rather than objects to be cared for then attitudes may change. Then they can start to perceive residents in terms other than as passive recipients of care.

The recently published work by Allan (2001) does suggest that staff can perceive people with dementia as more competent and communicative than they had expected and reap rewards in the quality of the relationships they then share. For this to come about, there is a need for flexibility of

working practices within care settings, to allow the staff the time that would be required.

Relatives are influenced by their previous relationships with the person. However, they may be able to dissolve the reversed dependency image by giving social support. I believe this would improve the relationship for both parties, and restore personhood.

Similarly, communities that perceive people who have dementia as having something to contribute despite impairments, may encourage participation in community activities. As long as preferences are respected, the benefits to people with dementia are almost certainly to be in improved access to choices.

These implications point towards improved relationships for all parties. If this can be brought about by alternative perceptions of people with dementia there will be particular benefits to them. As Kitwood said of personhood within the context of relationships: 'It implies recognition, respect and trust' (Kitwood, 1997: 8).

I would assert that work to find appropriate ways to aid communication for and with people with dementia should continue. In the quest to find ways for power relations to be redressed, care to avoid previous mistakes that disable, patronise and infantilize people with dementia, should also be appropriate ways to aid choice and voice.

Like many of the metaphorical journeys into dementia that were shown in Chapter 2 (Bayley, 1998; Davis, 1984; McGowin, 1993; Rose, 1996) this ethnography has been a journey. It has been a journey of discovery, but what I hope is apparent is that this discovery was not of Alzheimer's disease but of socially competent and actively participating people who also have dementia. Through this ethnography my intention has been to facilitate these participants' voices and give others the opportunity to hear.

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Appendix A

Research plan submitted to Deer View Grange Nursing Home for negotiating access to research

Title: Relationships that people with dementia have with others

Type of study: Ethnographic – very in depth research consisting of observation and interviews.

Stage I: Observation of the group

I would like to spend an initial period of visiting at differing times around the clock to investigate whether there is a pattern of things occurring at regular times of the day. This would also serve as a familiarisation exercise, I would get used to and learn about the environment and people would get used to me being around. It would be an appropriate time for me to also explain to staff what I will be trying to do. After this initial period, I would like to observe residents, looking at relationships within and beyond the group; at who residents are conducting relationships with and what appears to be the basis of these relationships. My expectation is that other issues surrounding relationships will emerge during this period. I anticipate this stage lasting for about 16 weeks. The group that I would like to study would be one of the natural units of twelve people with dementia living in the Nursing Home. At this stage, I would restrict my observation to the ‘public’ areas of the Home; the lounge and dining areas, unless invited by individuals to visit private rooms. In order that my presence appears as natural to the group as possible I would be happy to help serving meals and drinks if these coincide with my visits and would welcome the opportunity to participate with the residents in activities taking place in the public areas. Any recording of data at this stage would consist of notes taken after leaving the residents.

Stage II: Focus on individuals from the group

Following directly on from *stage I* of the research, I would like to spend time with individual members from the group. In this stage of the research I would anticipate visiting an individual about ten times, for about 2 hours a visit. This would be time when I would shadow an individual, observing and talking to them. I would also like to conduct an audio-taped interview with them, and separately with any of their contacts (including carer assigned to individual, about 30 minute interview). This would facilitate building in-depth knowledge and a rounded view. In this stage, it would be preferable if I could conduct the taped interviews privately. Additionally, with the individual’s permission, it may be of benefit to visit the person’s room and initiate discussions on personal possessions and photographs, which may serve as prompts. The size of the sample

for this stage would hopefully be 8 to 10 individuals, and the total timespan would be 16 to 20 weeks. Confidentiality of residents would be respected at all times and I would like to offer assurances that no individual or the nursing home would be identified in either the thesis or any resulting reports and articles.

Stage III: Gradual withdrawal

It is hoped, that by this stage in the project I will have built relationships myself with members of the group, and that they will have become used to seeing me on a regular basis. For this reason, and in order to fill any gaps in my research, I would like to reduce my visits to the group gradually. I don't want people to feel a sense of loss at the close of the research, and I will use this time to assess how best to minimise any impact upon individuals. I would anticipate this stage lasting about 4 weeks, but recognise the need for flexibility in this.

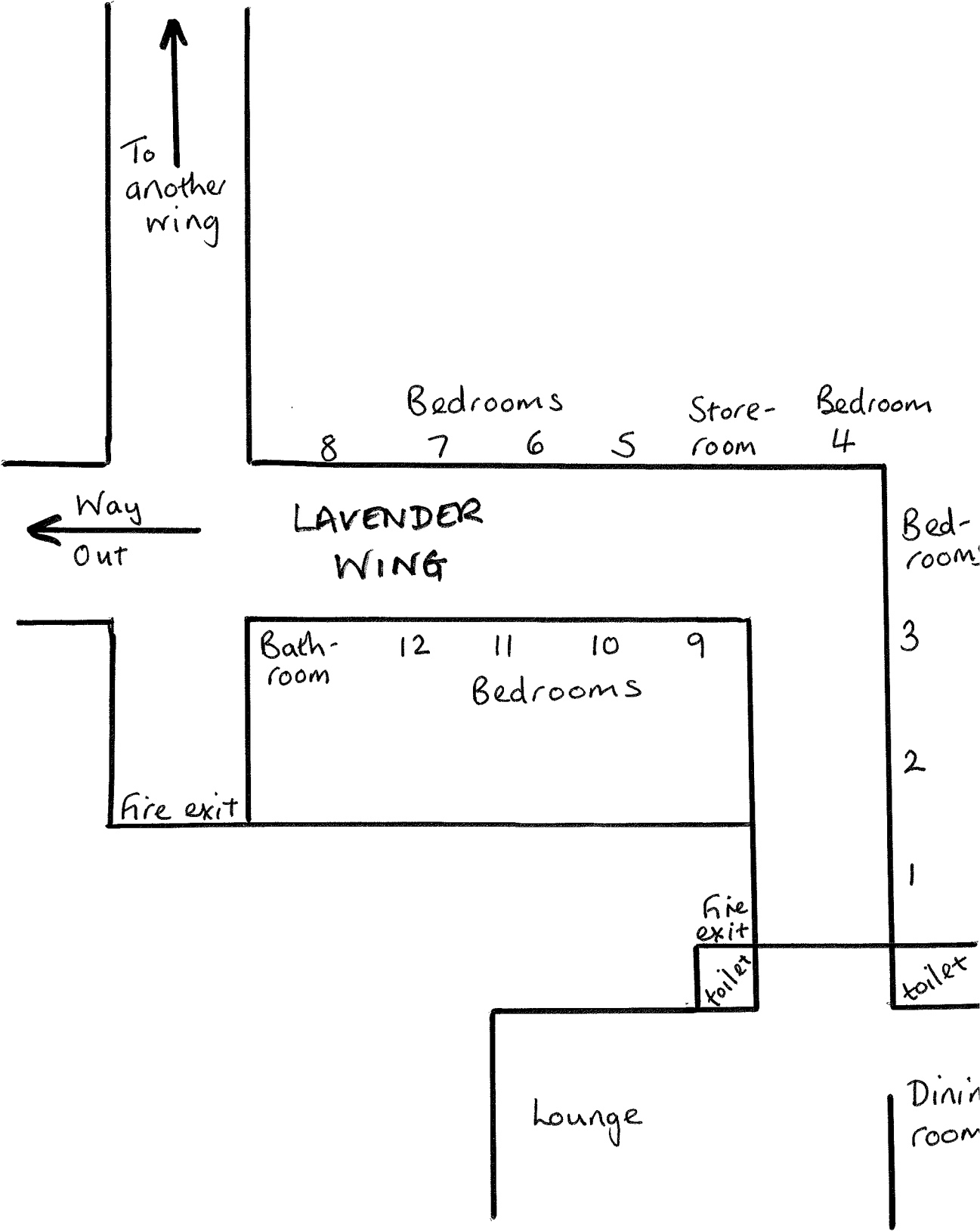
Informed consent:

I will produce information sheets about the study for residents and their representatives, and be happy to meet with or talk to those who may like to know more about the research. In this way informed decisions about participation in the study can be reached and written consent obtained.

Stage II of the research is the most sensitive and obviously requires consent to participate from individuals and their representatives. *Stage I* is concerned with gaining a general overview of the group, and it is thought that if consent is negotiated with group members, then collective consent from a representative of the group may be appropriate. I will produce information sheets about the study for participants and their representatives.

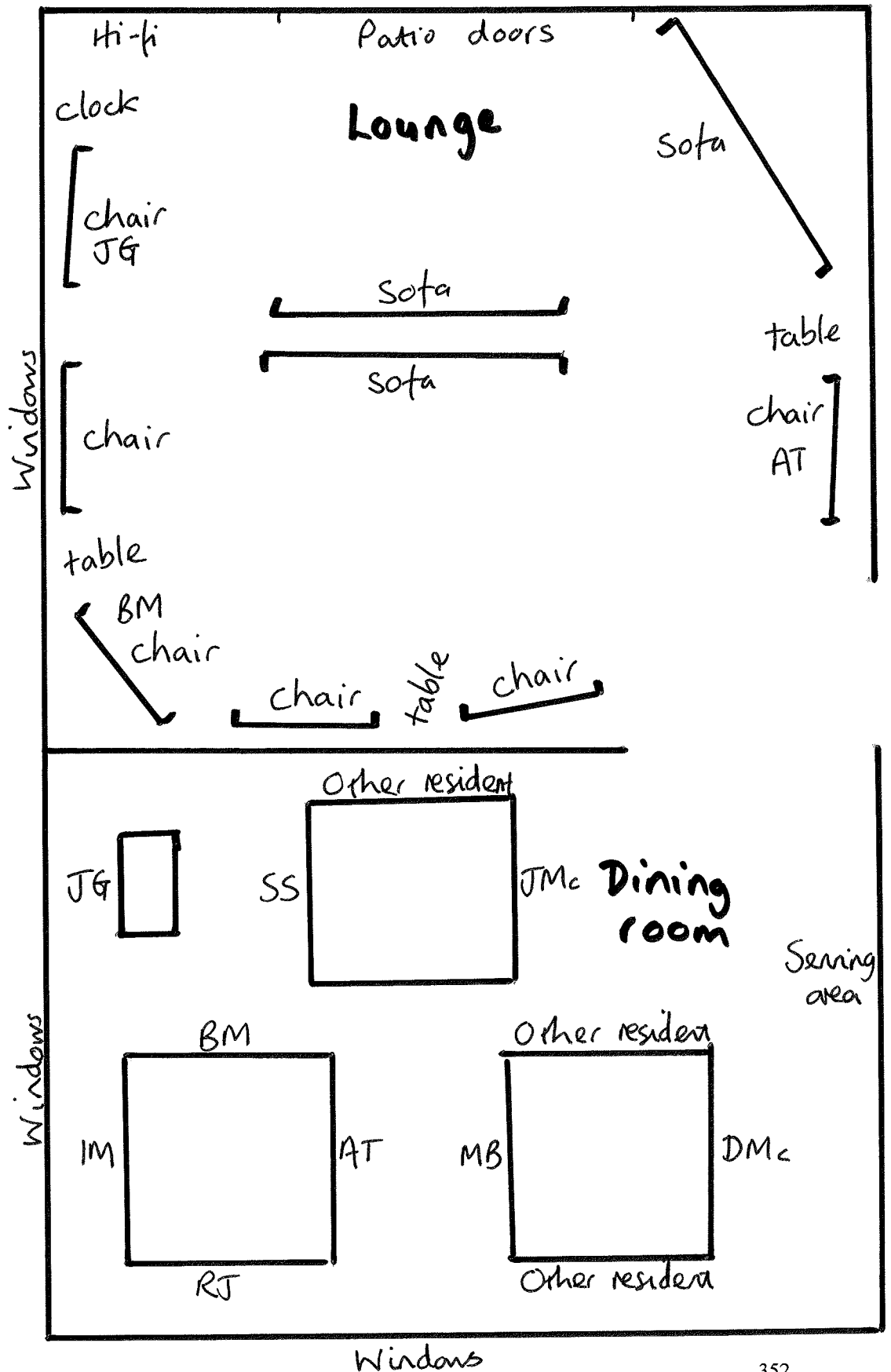
Appendix B

Plan of Lavender Wing



Appendix C

Plan of lounge and dining room of Lavender Wing



Appendix D

Coding of nodes for structuring data in NUDIST

Q.S.R. NUD.IST Power version, revision 4.0.

Licensee: Gillian McColgan.

PROJECT: Thesis project, User Gillian McColgan, 11:10 am, May 9, 2001.

- (1) /Setting and residents
- (1 1) /Setting and residents/Setting
- (1 2) /Setting and residents/Residents
- (1 2 1) /Setting and residents/Residents/JG
- (1 2 2) /Setting and residents/Residents/IM
- (1 2 3) /Setting and residents/Residents/RJ
- (1 2 4) /Setting and residents/Residents/MB
- (1 2 5) /Setting and residents/Residents/DMc
- (1 2 6) /Setting and residents/Residents/BM
- (1 2 7) /Setting and residents/Residents/AT
- (1 2 8) /Setting and residents/Residents/SS
- (1 2 9) /Setting and residents/Residents/JMc
- (1 66) /Setting and residents/Life History
- (1 66 65) /Setting and residents/Life History/Work
- (1 66 67) /Setting and residents/Life History/Marriage
- (1 68) /Setting and residents/Age

- (2) /NH Culture
- (2 1) /NH Culture/Possession and Choice
- (2 1 19) /NH Culture/Possession and Choice/Possession
- (2 1 19 40) /NH Culture/Possession and Choice/Possession/Money
- (2 1 33) /NH Culture/Possession and Choice/Choice
- (2 1 33 5) /NH Culture/Possession and Choice/Choice/Music
- (2 1 33 32) /NH Culture/Possession and Choice/Choice/Rearrange
- (2 2) /NH Culture/Routine
- (2 2 50) /NH Culture/Routine/Atmosphere
- (2 2 63) /NH Culture/Routine/Time
- (2 9) /NH Culture/Power and Control
- (2 9 35) /NH Culture/Power and Control/Whoops I didn't know you were there
- (2 9 37) /NH Culture/Power and Control/Surveillance
- (2 34) /NH Culture/Medicalization
- (2 34 29) /NH Culture/Medicalization/Toileting
- (2 49) /NH Culture/Privacy
- (2 62) /NH Culture/Infantilization

- (3) /Dementia and Emotions
- (3 31) /Dementia and Emotions/Emotions
- (3 31 1) /Dementia and Emotions/Emotions/Amusement
- (3 31 2) /Dementia and Emotions/Emotions/Love
- (3 31 3) /Dementia and Emotions/Emotions/Attachment
- (3 31 39) /Dementia and Emotions/Emotions/Regret
- (3 31 43) /Dementia and Emotions/Emotions/Compassion
- (3 31 44) /Dementia and Emotions/Emotions/Loss
- (3 31 48) /Dementia and Emotions/Emotions/Fear
- (3 31 51) /Dementia and Emotions/Emotions/Anger
- (3 31 52) /Dementia and Emotions/Emotions/Excitement

(3 31 56) /Dementia and Emotions/Emotions/Upset
 (3 31 69) /Dementia and Emotions/Emotions/Disappointment
 (3 59) /Dementia and Emotions/Dementia
 (3 59 15) /Dementia and Emotions/Dementia/Wandering
 (3 59 42) /Dementia and Emotions/Dementia/Insight
 (3 59 45) /Dementia and Emotions/Dementia/Agitation
 (3 59 46) /Dementia and Emotions/Dementia/Confusion

 (4) /Interaction
 (4 1) /Interaction/With or about
 (4 1 1) /Interaction/With or about/Self
 (4 1 2) /Interaction/With or about/Co residents
 (4 1 2 7) /Interaction/With or about/Co residents/Friends
 (4 1 2 10) /Interaction/With or about/Co residents/Others
 (4 1 3) /Interaction/With or about/Staff
 (4 1 3 1) /Interaction/With or about/Staff/Management
 (4 1 3 2) /Interaction/With or about/Staff/Nurses
 (4 1 3 3) /Interaction/With or about/Staff/Receptionists
 (4 1 3 4) /Interaction/With or about/Staff/Care staff
 (4 1 3 5) /Interaction/With or about/Staff/Domestics
 (4 1 4) /Interaction/With or about/Researcher
 (4 1 8) /Interaction/With or about/Visitors
 (4 1 12) /Interaction/With or about/Family
 (4 1 21) /Interaction/With or about/Mother
 (4 1 23) /Interaction/With or about/Pets
 (4 1 41) /Interaction/With or about/Local people
 (4 1 47) /Interaction/With or about/Husband
 (4 16) /Interaction/Retained social skills
 (4 16 36) /Interaction/Retained social skills/Religion
 (4 24) /Interaction/Death
 (4 38) /Interaction/Mistaken identity
 (4 55) /Interaction/Role play

 (5) /Margins and Boundaries
 (5 1) /Margins and Boundaries/Rule breaking
 (5 1 20) /Margins and Boundaries/Rule breaking/Deviance
 (5 1 20 3) /Margins and Boundaries/Rule breaking/Deviance/Smoking
 (5 1 53) /Margins and Boundaries/Rule breaking/Resistance
 (5 1 53 22) /Margins and Boundaries/Rule breaking/Resistance/Got to get out
 (5 30) /Margins and Boundaries/Boundaries
 (5 58) /Margins and Boundaries/Rules
 (5 58 57) /Margins and Boundaries/Rules/Compliance
 (5 64) /Margins and Boundaries/Insiders/outsidiers
 (5 64 11) /Margins and Boundaries/Insiders/outsidiers/Distancing

 (F) //Free Nodes
 (F 1) //Free Nodes/E&D new coding
 (F 13) //Free Nodes/Activity
 (F 13 17) //Free Nodes/Activity/Celebrations
 (F 13 18) //Free Nodes/Activity/Outing
 (F 13 28) //Free Nodes/Activity/TV/Video
 (F 13 54) //Free Nodes/Activity/Bored
 (F 13 61) //Free Nodes/Activity/Waiting
 (F 14) //Free Nodes/Hairdressers
 (F 25) //Free Nodes/Presentation
 (F 25 27) //Free Nodes/Presentation/Jewellery
 (F 26) //Free Nodes/Reflexivity